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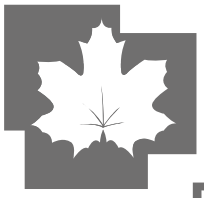

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REVIEW ARTICLES

The importance of Professor Américo Piquet Carneiro for health in Brazil

The begining of September 2019 will mark the 110th anniversary of the birth of Américo Piquet Carneiro, a native of the state of Ceará, who came to Rio de Janeiro at the age of five, graduated in medicine at the National School of Medicine in 1934, and embarked on a career as doctor and teacher and a maker of dreams so increasingly publicly-focused that almost all became reality. Those who had the privilege of knowing Professor Piquet – a she was affectionately known by all – especiallyin the final years of his life, will recall the last of those dreams: the implantation of the Care Center for the Elderly (or NAI) within the Pedro Ernesto University Hospital and the creation of the Open University of the Third Age (UNATI) within the framework of his beloved UERJ. Anyone familiar with teaching hospitals in public universities, which are in an almost constant state of crisis, will understand the difficulties involved in the creation of the NAI, the embryo of UNATI, which included securing a physical space for the new operation and the hiring of staff, a task made more complicated by the pioneering multi- and interdisciplinary approach of the project. This entire process was led by a professor who had been retired for more than ten years, was already over 80 years of age, and whose passionately held motto was *"what will happen in Brazil in 2025, when we have the sixth biggest elderly population in the world, with more than 30 million people"*. For Professor Piquet the title of "Professor Emeritus", which for many represents just another honorable recognition from the university from which they retire, was merely a passport to manufacture more dreams...and how he manufactured them! The Care Center for the Elderly was born! It emerged as a fragile little plant among leafy trees, then added emotions and hearts, and was watered by the hopes of young professionals and the expectations of the elderly who taught them, day after day, that life is about coming together! The dream was then expanded to the University, in the shape of the UNATI project, a more complex leap, perhaps into calmer waters, perhaps not! At a more advanced age, with lessened vigor, but with courage and faith preserved! Américo Piquet Carneiro did not live to see the inauguration of UNATI, passing away a few months before, but the ingredients and arrangements for its creation were all chosen and orchestrated by him.

How did he achieve all this? How did he manage to transfer the Pedro Ernesto Hospital– the "cherry on the cake" of the hospital network of the Health Department of the newly created state of Guanabara – to a young university that was changing its name for the third time? How did he organize the construction, for the transfer of basic courses, of the building that today bears his name, physically guaranteeing alink with the Hospital? How did he plan and set up an Integral Medicine Outpatient Clinic at a time when the emphasis was on rapid specialization? How did he live, with so much pain, but without losing his composure, through one of the saddest moments in the history of the college of which he was the director, the death of Luiz Paulo and the injuries to several other students on October 22, 1968? How did he manage to conceive and create the Institute of Social Medicine in the darkest days of the military regime? We could list other

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achievements, such as the incorporation of the Rachel Haddock Lobo Nursing School into the then Guanabara State University, the creation of the Biological Sciences Course and the Roberto Alcântara Gomes Institute of Biology, the establishing of the first master's degrees in health and the Piquet Carneiro Health Clinic, all of which should only increase our sense of wonder at someone who managed to accomplish all this in a generation, without ostentatiously wielding power, without explicitly currying favour with politicians, without making demands on alumni and patients in influential positions, without raising his voice, without ever exhibiting any sorrow or resentment at the considerable difficulties he faced. Given the diversity and the volume of his achievements, a simple interpretation is almost impossible. Maybe we can think of some possibilities based on how he presented himself to the world. First, the books! Most of those who knew him say that he almost always walked around with books, often giving them away like a farmer tosses seeds to the ground, without asking whether they will grow or not! Secondly, knowledge! His almost obsession-like need to seek out new knowledge, from an era in which Immunology was still a mere appendage of Microbiology in a textbook, included proposing that environmental health officers have sufficient knowledge in the field, and the recommendation that oncologists and geriatricians study inflammatory processes in more depth, as well as insisting on greater knowledge of the connective tissue structure. And finally there were his actions! It was a constant theme of his life, to act silently and patiently, with frank and transparent goals, to carry out actions whose essential characteristic was to empower people, from his most qualified pupil to the humblest employee, from the most important media figure to the most anonymous worker, all seemed to be left with the same sense of belonging, the feeling of being part of a network where everyone was of equal importance and had the same power to achieve an objective which then became something of value for everyone. But how could he make reading, knowledge, and action such an effective equation? Perhaps because of his capacity to engage in dialogue, expressed by an always kindly attitude to people and a way of listening carefully to them, perhaps because of his ability to devote himself to a cause, the gift of himself, perhaps because of his faith, which went much further than the religious – which he carried with him as well – the faith he had in people, in the sense that they all have deep within their being the desire and intention to do things that are greater than themselves and that surpass their existence...

Francisco Barbosa Neto

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Coordination of care increases the quality of care and reduces costs

Renato Peixoto Veras[1]
João André Cruz Gomes[2]
Sandro Tadeu Macedo[3]

Abstract

The study addresses a health care model of the elderly practiced by a health care provider in the city of Rio de Janeiro, RJ, Brazil, focusing on the age group of the elderly, population segment in which the greatest misconceptions are identified. The current assistance models did not consider the deep transformations observed in the new epidemiological and demographic reality of the country. Considering that the aging process in Brazil is relatively recent, the article presents a proposal for a contemporary care model, recommended by the most important national and international health agencies as the most suitable for better care, focusing on the promotion, prevention of health care and the coordination of care, in order to avoid excesses, waste and fragmentation. The assistance and financial results of this study display very positive figures and indicate the path to be taken by healthcare companies. The model of remuneration for service providers and the indicators used for the establishment of bonuses are also presented, since they function as an instrument that stimulates and values good health care practices. This text is concerned with a higher quality, more resolutive and cost-effective care model, which is corroborated by the operator's results presented here.

Keywords: Health policies. Human aging. Elderly. Diseases prevention. Coordination of care. Payment for performance.

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INTRODUCTION

One of mankind's greatest accomplishments has been to achieve longevity, which has been accompanied by a substantial improvement in the health parameters of populations, although these achievements have been far from equitably distributed in different countries and socioeconomic contexts. Reaching old age - once the privilege of a few - has become the norm even in the poorest countries. The challenge, therefore, is to add quality to these additional years of life.

This demographic transition and the improvement in Brazil's social and economic indicators, compared to previous decades, have led to the expansion of the elderly population and greater fiscal pressure on public and private health systems. If this portion of the population increases, chronic diseases and expenditures also naturally increase[1]. One of the results of this dynamic is the growing demand for health services, which can simultaneously generate scarcity and/or resource constraints. Hospital admissions become more frequent and bed occupancy times are greater than in other age groups. The diseases that affect the elderly are mostly chronic and multiple, require constant monitoring, permanent care, continuous medication and periodic examinations[2].

With so many adverse situations, care of the elderly should be structured in a special manner. The current provision of health services fragments care for this age group, with multiple expert consultations, non-sharing of information and numerous drugs, clinical and imaging exams, among other procedures that overload the system, have a serious financial impact at all levels and do not generate significant benefits for health or quality of life[3].

In recent decades, it has been shown that most of the public health problems affecting the population - not only communicable but also noncommunicable diseases - can be prevented. This is exemplified by the reduction in mortality due to cardiovascular disease, a reduction in the incidence and mortality of cervical cancer, the prevalence of smoking and the incidence of lung cancer in men. In summary: the burden generated by diseases can be avoided in both social and economic terms[4].

The monitoring of the health conditions of a given population, as well as their associated factors, is a key instrument for guiding prevention strategies, which should aim to: favorably affect the natural history of the disease; anticipate the appearance of complications; prevent exacerbations and complications of chronic diseases; increase patient involvement in self-care; and build a database of the chronically ill, that is, the overwhelming majority of the elderly.

According to the World Health Organization (WHO), a chronic disease has one or more of the following characteristics: it is permanent, produces incapacity or disability, is caused by irreversible pathological disorders and requires long periods of supervision, observation or care. In general, chronic diseases begin slowly, have a long or uncertain duration, and do not have a single cause[5]. The treatment involves changes in lifestyle and continuous care that does not usually lead to healing, but allows the disease to be kept under control and improve the patient's quality of life, in order to prevent or ameliorate functional decline. Most chronic diseases are related to age, poor eating habits, sedentary lifestyles and stress, and so can be prevented and/or delayed. It means that despite the disease, it is possible to live a fuller life for a longer time.

Programs aimed at this population should be built on the basis of integral care, with the reference health professional and their team playing a leading role, managing not the disease, but the health profile of the patient. Often, the treatment of a manifestation can only be carried out with the reduction or suspension of other actions that were being performed[5].

A contemporary model

In projects outside Brazil, a general practitioner or family doctor deals with 85% to 95% of their patients, without the need of a specialist. In addition, this doctor can employ health professionals with specific training (in nutrition, physiotherapy, psychology, speech therapy, and other specialties). It is the general practitioner who makes recommendations and referrals[6].

The English model, the National Health Service (NHS), employs generalist medical figures with high-resolutive capabilities - so-called general practitioners (GPs) - who establish a strong bond with their patients. Access to these professionals is guaranteed to everyone regardless of income or social status, similar to the Brazilian Unified Health System (or SUS). When registering with a GP, British citizens receive free public health care in units composed of general practitioners and nurses. Any necessary treatment, provided it is not of extreme urgency or due to an accident, is performed there[7]. The American model, on the other hand, chooses to refer patients to numerous medical specialists. These are two rich countries, with great medical traditions. However, they use different systems and produce quite different results[8].

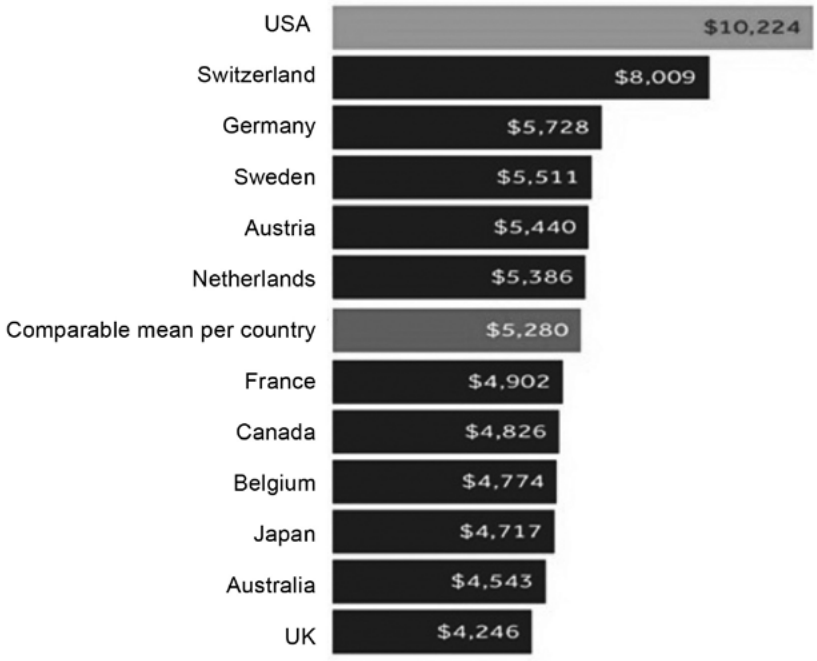
In Brazil there is an excess of consultations by specialists, as the current care model prioritizes the fragmentation of care[9]. However, the discussion about population aging brought about by the new epidemiological and demographic reality suggests a need for the creation of a more resilient and effective model[10]. One question therefore emerges: if everyone is discussing this issue and the solutions are already part of decision-making meetings, why is the situation unchanged? Why do leaders and managers not change the situation?

In order for the health sector – particularly in the elderly segment – to reorganize itself, one of the items to consider is trust. Today society is suspicious of what is offered. In this climate, any proposal for change is viewed with reservations. Anything that is multifactorial and built over many years is difficult to transform[11].

Quality of care demands greater awareness among health managers and society. It is argued that it would be expensive to apply instruments that provide more qualified care, accreditations and certifications, yet good services are more effective in terms of cost, generate less waste and better patient care results. In some countries, accreditation and the evaluation of quality indicators are mandatory requirements. In Brazil, however, volume is valued and rewarded. A policy of stimulating quality is lacking. Patients do not always recognize it as a necessity. And both the public and private health systems perceive it as an additional cost.

Explosive costs

A recent study by the Organization for Economic Cooperation and Development (OECD) in developed countries shows the difference between health care costs in the United States and other rich countries which offer good quality care - where, of course, health care expenditures are greater than in developing countries. Still, the spending of the Americans is higher. In 2017, it was US$ 10,224 per person, 28% higher than Switzerland and more than double the United Kingdom (see Figure 1). These data reinforce the view that mass investment in disease treatment is not enough. Considering the aging of the global population, health costs tend to be an increasing burden for society, as shown in Figure 2. This demonstrates a reduction in the costs of activities that require the use of new technologies, as opposed to costs related to hospital services. It is imperative to change the logic of care[12].

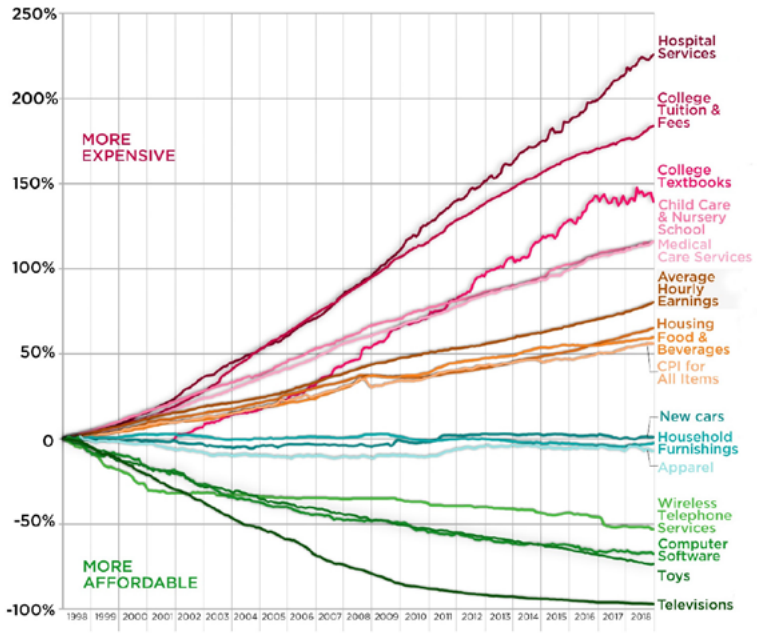


PPP: Purchasing power parity is a way of measuring economic variables in different countries, so that irrelevant changes in the exchange rate do not distort comparisons.

The US value was obtained from the 2017 National Health Expenditure data.

Source: *KFF analysis of data from National Health Expenditure Accounts and OECD – Get the data – PNG. Peterson-Kaiser, Health System Tracker.*

Figure 1. Health costs per capita, US dollars, adjusted by Purchasing Power Parity (PPP), 2017.



Source: *Price Changes Over the last 20 years prove the economy is rigged* (https://howmuch.net/article/price-changes-in-usa-inpast-20-years).

Figure 2. 20 years of price changes in the USA. Goods and Services of selected consumers, salary (Jan. 1998 to Dec. 2018).

The innovation required

Care must be organized in an integrated manner and must be coordinated along the care path, in a network of logic, from entry into the system to care at the end of life[13]. Suitable models of health care for the elderly offer a proposal for a line of care focused on actions of education, health promotion, prevention of preventable diseases, postponement of illnesses, early care and rehabilitation[14]. The model should be based on the early identification of the risks of user frailty. Once risk is identified, the priority is to intervene before the event occurs, reducing the impact of chronic conditions on functionality. The idea is to monitor health, not the disease. Thus, the best strategy for proper care is to use the logic of permanent accompaniment, varying only the levels, intensity and scenario of the intervention[15].

There is a general understanding that care for the elderly goes beyond health. In addition to diagnosis and prescription, social participation, physical and mental activities are important elements for maintaining functional capacity. But especially in supplemental health, there is still much difficulty in understanding these actions as an integral part of care - a tendency to separate "social" from "healing" actions. It is also of fundamental importance, especially today, that quality information and electronic medical records register both clinical and "social" actions, and that this registry is available in the cloud and accessible by mobile, so that doctors and other health professionals can monitor the client at any time.

Regarding the remuneration model of health professionals, why not adopt performance related pay? Linking results to the form of remuneration is a powerful tool for quality of care. And the model should be of the win-win type, in which all involved benefit, especially the patients.

In order to put into practice the necessary actions for a healthy aging with a good quality of life, care for the elderly must be rethought and redesigned with a focus on these individual and their particularities. This will bring benefits, quality and sustainability not only for the elderly population but for the Brazilian health system as a whole[5]. It is time to show the capacity to unite efforts that turn theory into a health model of universal quality. We do not desire the fragmentation of the SUS, nor the increase in the number of bankruptcies among private health care companies.

The challenge is to ensure this new care model is accepted by the client, as trust is an indispensable factor for the process to occur as planned – and one cannot ask someone to trust something they know nothing about. There is little point in saying that this model is the best if it is not implemented by supplementary health services. Society needs to understand this proposal extensively to be convinced of its benefits[16]. Otherwise, it will continue to opt for the "siren song" of excess and consumption, which burden the system, generate ever higher costs and render long-term care unfeasible.

Well-executed care coordination

We shall now demonstrate the successful experiment performed by a health care provider in two of its units in the city of Rio de Janeiro. The study focuses on the performance indicators of the company, which offers a specific program for the elderly population that has been providing excellent results.

The change in care logic encountered some resistance from health professionals and especially from clients, who were reluctant to accept having fewer doctors to rely on. After the first year of the new model, however, the situation has changed. The present study provides an analysis of a 12 month period - March 2018 to February 2019 - as a demonstration that it is possible to change results for the better and generate loyalty.

The geriatrics and gerontology program has two units in the city of Rio de Janeiro, in the neighborhoods of Copacabana and Tijuca, regions with a high proportion of elderly persons. Care is provided by general practitioners and geriatricians, as well as specialized multiprofessional teams (nurses, physiotherapists, nutritionists, psychologists and social workers).

Now in its fifth year of operation, the program is structured in the form of a care model that focuses on integral care and prevention through the continuous monitoring of the health conditions of its members and the coordination of all settings of care. The present survey considers the total results of the units, without distinguishing between location, as the model practiced is exactly the same in both.

This health care provider provides care to clients aged 40 and over, but its largest concentration of patients is in the 60 to 79 years range, representing 76.7% of its clientele. The average age of clients is 69.1 years. Clients with chronic diseases, unhealthy living habits or with a pre-disposition for such pathologies are accepted. Entry occurs through active searching, spontaneous demand, medical recommendation and de-hospitalization.

The centrality of the model is based around the managing or attending physician. This is the health professional who guides the process. If an opinion or intervention by another colleague is required, he or she will refer the patient to a specialist. The handling of the case, however, is the responsibility of this attending physician. After consultation with the specialist, everything is recorded in the patient's individual medical record.

The program is based on a pairing formed by a general practitioner (qualified geriatrician) and nurse. Together, they have the responsibility of monitoring the health of around 360 patients. The doctor, who works 20 hours a week, performs clinical management; the nurse, the coordination of care, monitoring the health conditions of their client list and consolidating their reference role through reception and the strengthening of bonds.

The proposal of welcoming, monitoring and providing health support within a broad concept that considers clinical stabilization as a constant goal is one of the premises of the program. Its efficacy is attested by the financial results obtained, which is only possible with the high levels of adherence of the participants, who perceive they are receiving more intense care.

In these health units, an important space is the social center, which has a fundamental role as a place of integrating several actions of promotion, prevention and education. There are meetings and interactions with pedagogical goals, aimed at the elderly, such as health workshops, therapeutic groups, yoga, ballroom dancing, psychology groups, nutrition, singing, postural orientation, pelvic and muscular strengthening, with the participation of multidisciplinary professional teams. This is a set of professionals from different academic backgrounds who contribute the specific tools of their area of knowledge and performance. The objective is to reduce the problems of solitude among the elderly, to improve their social contact and to develop new abilities at a later age, as this is a stimulating space for the exchange of experiences, mediated by a pedagogical approach.

Entry

When there is interest in joining the program, an initial interview with the management team is scheduled. At this point, the basic premises are described, such as the single line of medical care, the importance of attending consultations regardless of symptoms or suffering from an active disease, and the monitoring process.

Initially, the functional evaluation of the elderly is carried out using the Functional Clinical Vulnerability Index-20 (IVCF-20) tool for the stratification of the risk of frailty. Throughout the process, other scales are also used, such as the Basic Activities of Daily Living Scale (Katz Scale), the Geriatric Depression Scale (Yesavage Scale) and the Instrumental Activities of Daily Living Scale (Lawton Scale)[17-19]. Following this evaluation, the geriatrician and nurse pairing define an individual therapeutic plan with periodic consultations, referral to multidisciplinary teams and social centers and, if necessary, the evaluation of medical specialists.

For the success of the model, it is fundamental that the client is informed about its unique characteristics: integrality, individualized care from the attending

physician and nurse, constant evaluations, the support of a health team and the overall nature of the care. The program is part of a prevention platform that includes palliative care projects, multi-level home care, reception and targeted hospital care, which is the network of the internist doctors of the health providers who accompany members in certain hospitals where there are exclusive beds for this purpose.

By monitoring health rather than illness, the model directs the investment of system resources towards early intervention, resulting in more generous chances of rehabilitation and a reduced impact on functionality.

Doctor remuneration

Performance-related pay was established by the provider for this specific program and establishes bonus levels of up to 30% in compensation per quarter. Every three months, an evaluation of the performance of the professional is made based on previously determined indicators. Each point obtained adds a bonus of 5% of his or her salary.

One of the evaluation items is the percentage of consultations of the doctor's patient list every quarter. As one of the premises of the program is that there is a need for four medical consultations per year, quarterly consultations is required for all clients linked to the doctor. In other words, every client of the program is attended by their doctor four times a year. Non-attendance situations are analyzed on a case-by-case basis.

Attendance and punctuality are prerequisites of the bonus system, and are fundamental for guaranteeing the number of consultations – a factor of quality for the operation of the service. Another requirement of the scoring program is the proper recording of information and possible hospitalizations in the electronic records of clients. Rigid control by the team determines the economic-financial success of any initiative or project.

The bonus was initially established only for geriatricians, but the success of this mode of remuneration was such that the company decided to extend the benefit to all healthcare staff. The items chosen for the establishment of differentiated performance criteria are related to the theoretical principles that guide the actions being carried out. As established assumptions, these indicators are constantly evaluated.

A customer satisfaction survey in line with the methodology of the Net Promoter Score (NPS) is continuously performed in the healthcare units of the provider. One of the issues is an assessment of customer satisfaction with doctors. Al the doctors of the program at this provider are geriatricians with at least one postgraduate qualification. This is a requirement because professional excellence is a key to success.

Another basic principle is the resolutive capacity of the geriatrician. According to international studies[7], a general practitioner can resolve from 85% to 95% of the clinical situations of his or her clientele. Referrals to clinical specialists are the exception. The referral of up to 15% of clients on a doctor's patient list in a single quarter demonstrates good resolutive capacity, worthy of bonus points.

The engagement of users with the multidisciplinary team and the social center determines their bond with the program and its resolutive capacity. Thus, an item was included that evaluates the participation of the members of each patient list in consultations with the gerontologists of the team and in the collective activities of the social center, earning bonus points.

The main economic-financial indicator established for the evaluation of the program is the loss-ratio, which is why a greater weight was given to this item, and doctors can score up to two points in the evaluation of their performance in this category. By analyzing the recent history of the results, ambitious points goals were set. Although there is greater rigidity with this evaluation, the desired goals are already being achieved, and the win—win based stimulus to the professionals has been seen to be fair.

Bonus scoring

The items from the records of each physician evaluated quarterly are as follows:

1. Consultation percentage
   a. Consultation rate of 100% of patient list (1 point).
   b. Consultation rate of 90% to 99% (no points).
   c. Consultation rate below 90% (minus 1 point).

2. Client satisfaction survey (over 90%, 1 point)

3. Resolutive capacity of doctor
   a. Use of network for less than 15% of cases (1 point).
   b. Use of network of 80% to 85% (no points).
   c. Use of network lower than 80% (minus 1 point).

4. Participation in social center/workshops/ multidisciplinary team activities.
   a. Over 20% of clients from patient list (1 point).
   b. From 10 to 19% (no points).
   c. Below 10% (minus 1 point).

5. Medical loss ratio of patient list
   a. Below 70% (2 points).
   b. From 70% to 79% (1 point).
   c. From 80% to 99% (no points).
   d. 100% (minus 1 point).

For privacy reasons, the results of the bonuses of the doctors are not provided here. In terms of general information, however, all the doctors on the program have been subsidized in every quarterly evaluation. Variation occurred in the value of the bonus, because the percentages of some were superior to those of others.

Transition of care - hospitalizations

One of the main factors for controlling the costs associated with the program is patient accompaniment in each care setting. There should be no gaps in care when the patient is referred to the care network or when they require tertiary or hospital care.

The transition between care settings is accompanied by the management team, who emphasize the importance of the fluid flow of information, approaching the attending health professionals and seeking to preserve the principle of the predominant guidance of the geriatric doctor and nurse pairing.

The control of hospitalizations occurs via a determined flow in order to assist the clients, ensuring that caregivers are aware of their medical and treatment history, as well as understanding that such patients receive frequent follow-up monitoring and should return to their health team when the period of clinical risk is over.

In case of hospitalization, the patient is monitored on a daily basis through two strands. In one, the nurse maintains contact with the family to provide support, clarification or identification of needs (the patient's or the family's). The other involves a prevention manager, who acts as a liaison between the outpatient clinic and the hospital, with daily follow-up with the attending physician at the hospital. In hospitals where there is an internist (68% of hospitalizations of the program), this contact is facilitated and direct. In the others there is the support of the medical auditors or the care team.

With this aim being fulfilled, it can be attested that elderly hospitalization occurs more quickly, avoiding unnecessary procedures or hospitalizations in intensive care sectors, guaranteeing post-discharge guidance for mild care settings, without the need for consultation with various specialists. Everything converges into a higher quality of care with significant cost reductions, positively impacting the medical loss ratio among this group of patients.

RESULTS

The results of the operator studied are extremely positive and demonstrate the success of the model. The medical loss ratio has continuously decreased. In its first year, there was a negative impact, as the medical loss ratio was 108.20%. This rate refers to the first year of the project, reflecting the period

in which the clients were still receiving inadequate treatment from many doctors and hospitals. But from the second year onwards the numbers improved and better results were obtained in subsequent years, reaching the impressive mark of 56.6% in the final year (figure 3).

The medical loss ratio in 2018 was 61.8%. The figure 4 shows the month by month performance.

The medical loss ratio results of the final year of the program are below the expected level for the 60 years or older age group.

Another indicator that demonstrates excellent results is hospital admission. In the two units of the operator, there are 1,832 clients. In the last 12 months, there were 238 hospitalizations, totaling 1,160 days, with an average length of stay in the hospital unit of 4.9 days. The monthly average was 19 admissions and the hospitalization rate per 100 inhabitants was 12.99 - or 129.90 per thousand clients.

The statistics of the National Supplementary Health Agency (or ANS) were compared in terms of the hospital admissions of beneficiaries of the various modalities of Brazilian health care providers. In several years and across all comparisons, the results of the company studied herein were better[20].

It should also be noted that the ANS data comprise participants from all age groups, while the program of the provider studied here mostly involves the elderly. It would therefore be natural to imagine that the ANS numbers, as they include a significant proportion of young adults and children, would be superior (figure 5).

The chart shows (figure 6) the comparison of the hospitalization rate per thousand beneficiaries of the Program studied with self-management operators and also with the average of all health care providers in 2015, 2016 and 2017. The Program group is the result of the operator studied, followed by the self-management group, and all the health care providers for the years studied.

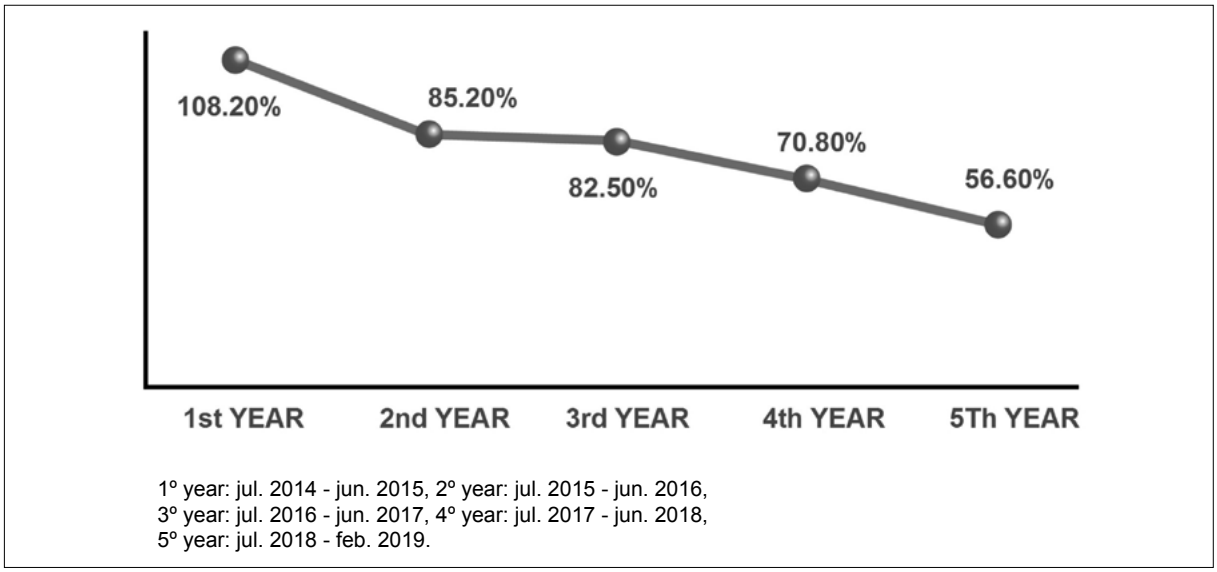


Figure 3. Medical loss ratio in last five years.

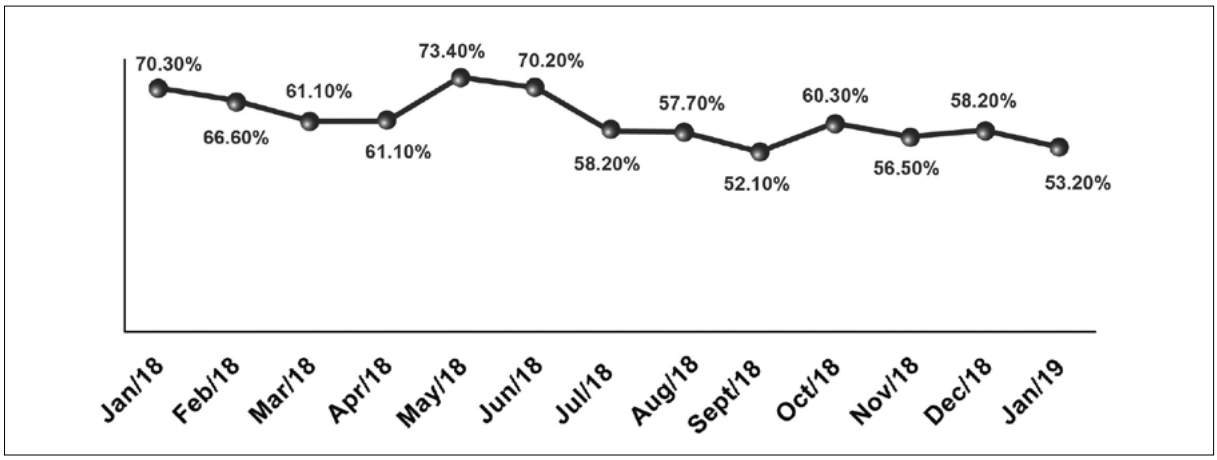


Figure 4. Month by month medical loss ratio 2018-2019.

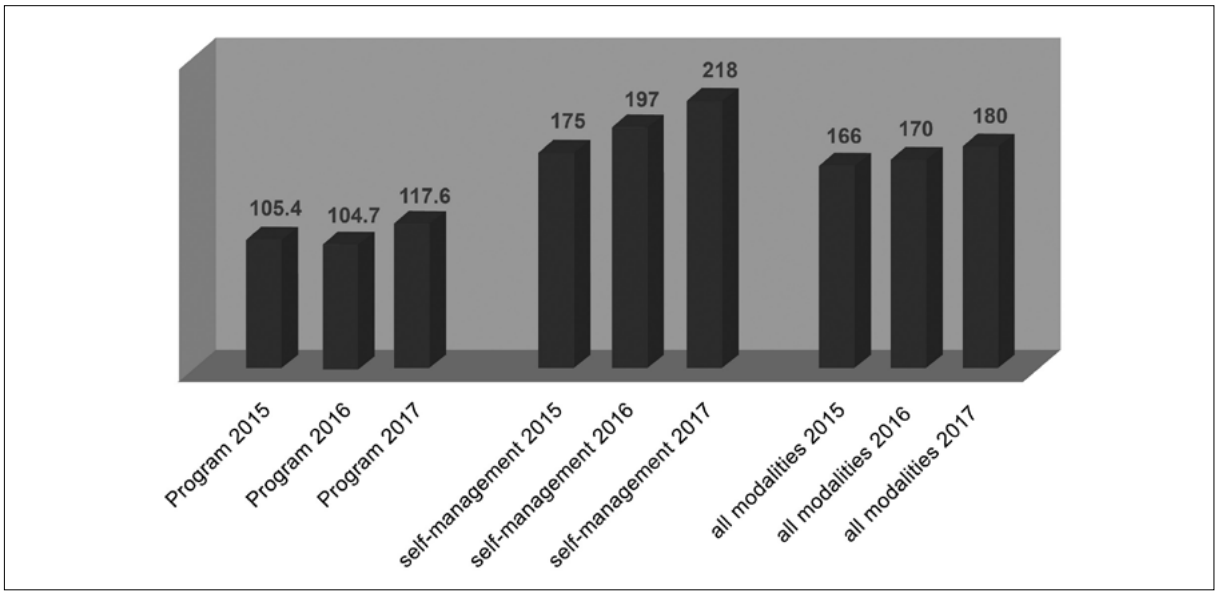


Figure 5. Hospitalization rate of studied groups.

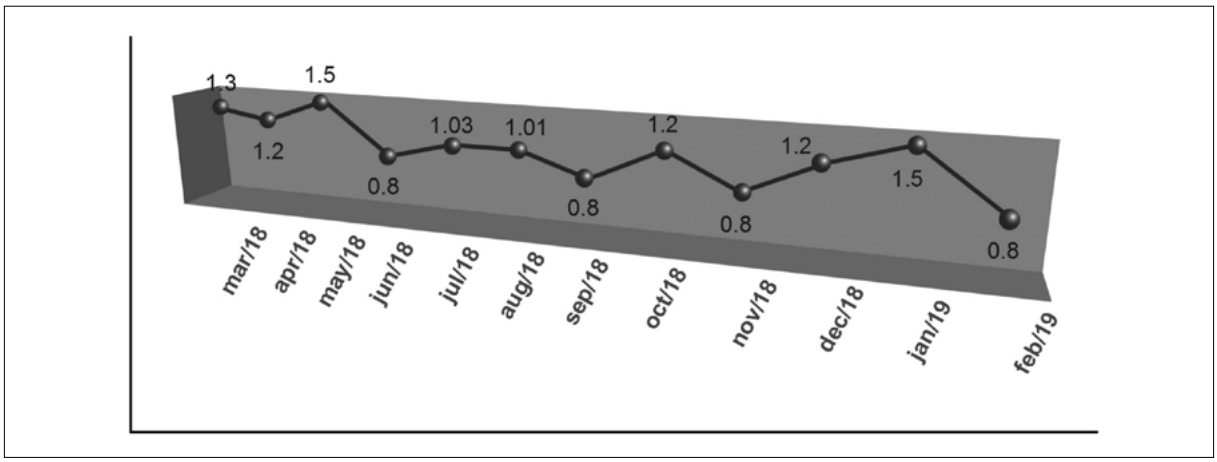


Figure 6. Hospitalization per 100 registered clients.

The analysis of the monthly hospitalization rate of the Program indicates that there is no major variation in the rate over time, demonstrating stability, the result of the control established through continuous and effective monitoring.

The importance of coordinating care

There are a number of suggestions for models of lines of care. It is important that each health institution has knowledge of its list of patients, their profiles and needs, in order to organize the delivery of service in the best way possible.

The model of this provider is in line with studies that suggest the implantation of coordination of care. Considering the hospital as a privileged place for healing is a conceptual mistake, as there must be several care settings prior to this stage. In the case of the elderly, hospitalization should occur only at the acute moment of the chronic illness and for the shortest possible time, or in the emergency room. The gateway to the system should be a facilitating setting for the client and their family to feel protected and supported. A welcoming reception is fundamental for those who arrive at the health service and a stimulus to developing confidence and loyalty.

Another important aspect is the emphasis on client participation in the activities of the social center. The data demonstrate the positive effect of this on reducing referrals to medical specialists. Furthermore, the professionals who run the activities are identified as team members and therefore have good credibility among clients. The importance of an effective information system and the use of new technologies for more frequent contact with the clientele was also identified. Without comprehensive information, there can be no effective monitoring.

For ethical reasons, we have preserved the confidentiality of the name of the health care provider, which authorized the use of the data and information presented herein following a prior request. Although the results presented refer to a health care provider, as this is a model of care, the proposal of this article can be perfectly applied to the public service. Based on the justification that good health care models should be practiced in both the SUS and the private sector, a good model should be used by the Brazilian population without distinction, whether the care is public or private.

CONCLUSION

In summary, an efficient model of health care for the elderly should involve the application of all levels of care: a well-designed flow of education, health promotion, prevention of preventable diseases, as well as the postponement of diseases and rehabilitation from illness. It begins in capitation and reception and ends only in the final moments of life, in the palliative care unit.

In order to reorient the health care of the elderly population and to organize the sector to enable better economic-financial and care results, it is sufficient that all those involved perceive themselves as responsible for change and allow themselves to innovate - which, in many situations, means rescuing simpler forms of care and values that have been lost within our health system.

We do not deny the importance of high-complexity forms of care and know that we will always need good hospitals. It is not logical, however, to turn hospitals into gateways to health systems.

It is vital that the debate on healing and care is included in discussions on vocational training and the organization of services. This transformation will make a great difference at this time of population aging, as we have learned that it is possible to grow old with sustainability, stable health and a good quality of life.

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What the elderly think of the care provided by health services

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Abstract

Objective: To identify the social representations of the elderly on the care provided in health services. *Method*: An exploratory study with a qualitative approach was carried out, in which 238 elderly persons were interviewed about the care they received in Basic Health Units and in a center of specialized care. Their discourse was recorded and transcribed in its entirety, and processed using Iramuteq software. The results were discussed using Social Representation Theory. *Results*: The elderly associated good care with being treated with respect, attentiveness and politeness; and, at the same time, the requesting of diagnostic exams, referrals to medical specialists and the prescription of medicines. In their imaginary, the Basic Health Unit hinders their access to specialized care and doctors in this service do not know enough to meet the needs of people of different age groups and health problems, meaning that consulting with a specialist becomes more important. In practice, they encounter difficulties related to delays in being attended to and obtaining appointments with specialists, diagnostic exams and with the first come, first served appointment system, which is further limited by the number of places and treatment of specific groups on certain days. *Conclusion*: The practices in the care provided to the elderly in health services need to be reviewed to offer humanized and qualified care that can meet their needs. Health professionals and managers should consider the different characteristics of the elderly when approaching care.

Keywords: Elderly. Delivery of Health Care. Primary Health Care. Health Evaluation.

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INTRODUCTION

In Brazil, the first contact between the user and the health system is generally made through Basic Health Units (BHUs), which include Family Health Units (FHUs), where medical appointments and examinations are arranged and less complex procedures are carried out. If the health needs of the user exceed the capacity of these services, then the patient is referred to higher levels of care and attention[1].

Ensuring the access of the general population to these levels of care and attention represents a challenge for the Brazilian Unified Health System (or SUS)[2], especially because, with the rapid aging process observed in the population, together with the increased incidence of chronic diseases, the use of health services by elderly persons have tended to become more common and frequent. This means that managers and health professionals must not only deal with the difficulties that are already present, to offer universal and comprehensive access, that is equitable, longitudinal and coordinated, but must also adapt their services and train their health teams, based on the needs of the elderly, to offer care with quality[3]. To achieve this, it is important to listen to the experiences of elderly and their opinions about what still needs to be improved[4].

As the perception of a given phenomenon (in this case, services in health care units) is affected by the way in which the individual regards the reality that surrounds them, based on a system of values and beliefs, the Theory of Social Representations (TSR), created by Serge Moscovici, provides a tool for the interpretation of the results found[5]. This author highlights three dimensions for the establishment of social representations: Attitude (position of subjects in the light of the object of representation), images or field of social representation (meanings given to the objects through concrete content responsible for the organization of the field of representation) and information (knowledge of any one group about a social object).

The question is therefore asked: What are the general social representations of the elderly about care services? To respond to this issue, the main purpose of the present study was to identify the social representation of the elderly about services in the health care segment.

METHOD

An exploratory qualitative study was carried out in the city of João Pessoa, in the state of Paraíba, in Northeastern Brazil, in two FHUs and also at the Center for Integral Healthcare for the Elderly (or CAISI). The FHUs surveyed are both inserted in the same social and economic context, and offer several services to their users, including: medical and nursing appointments; dental appointments and other services, home visits, application of vaccines, checking of blood pressure and blood sugar levels, distribution of medication. They also have special groups to monitor high blood pressure and diabetes and for Community Therapy.

When they arrive, the elderly people go to reception, explain why they have come, and are then attended to in order of arrival. If they need to be referred to a specialist doctor, or require any kind of medical examinations, these arerequested through an employee (appointment scheduler) who books the appointments. The elderly person is then informed of the date of the appointment, either on the same day or at a later date, as this depends on the availability of places offered by the municipality for a given service.

The CAISI serves an average of 2,500 elderly people per month, in 16 different specialties (as referred by the FHU), offering dentistry, nutrition and physiotherapy treatment, as well as activities that help healthy aging, including Memory Groups, Socializing, Posture Education, Physical Education, Flute and Dance. When they arrive at the service, the elderly people give their names to the attendants, who then check to see if there has been any prior booking made by the health unit. They are then called by order of arrival.

A total of 238 elderly people were interviewed (119 at the FHU, and the other 119 at CAISI), comprising a non-random sample, selected based on convenience and delimited by the criterion of data saturation,

which occurs when the data as accessed by the researcher displays redundancy, without the need to further expand the sample, as the information obtained is considered sufficient[6]. The following inclusion criteria were applied: Elderly people aged 60 or over; people who were attended at the same health service where the interview was conducted; those who did not have any cognitive deficit that would prevent the interviews from taking place; and acceptance of participation in the study. The Mini Mental State Exam (MMSE) was applied for cognitive appraisal, and eight elderly people who scored less than 27 points were excluded. In addition, 20 elderly people declined to participate, on the grounds of lack of interest.

The data were collected between January and May 2016, Monday to Friday, through a semi-structured interview, by a single interviewer who hadreceived prior training through lessons and theoretical training about this type of interview. The elderly people were individually approached in the waiting rooms of the CAISI and the FHUs, and then asked if they would be interested in taking part in the survey. If they said yes, they were invited to follow the researcher into a reserved room, made available by the service, where they were given further information about the goals of the research study, and also informed that they had the right not to participate in the study.

After meeting the criteria for inclusion and after signing a Free and Informed Consent Form (FICF) (or giving consent through their finger prints), the elderly people were invited to answer the question: "How would you evaluate the service you have received here?" The interview also included questions to characterize the interviewees: age, gender, level of schooling, marital status, and family income.

The statements were recorded and then fully transcribed, after which they were processed and analyzed using the Iramuteq software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*), version 0.7 alpha 2. The group of interviews was divided into smaller sections of text by the software. These Text Segments (TS) are then subjected to the Descending Hierarchical Classification method (DHC) and also to the chi-squared test (χ^2) to obtain the classes, which are established based on similarity of vocabulary as present in the declarations[7]. An in-depth reading was made for each class, by two researchers, to interpret the statements and identify social representations.

This study was approved by the Research Ethics Committee of the Hospital Universitário Lauro Wanderley (the Lauro Wanderley University Hospital) (or HULW), protocol number 261/09 and CAAE: 0182.0.126.000-09. The individual statements were identified as subject 1, subject 2 and so forth. To protect the identities of those working at the services considered, their professional classes were replaced by "health professional". The rest of the material was kept in its original version.

RESULTS

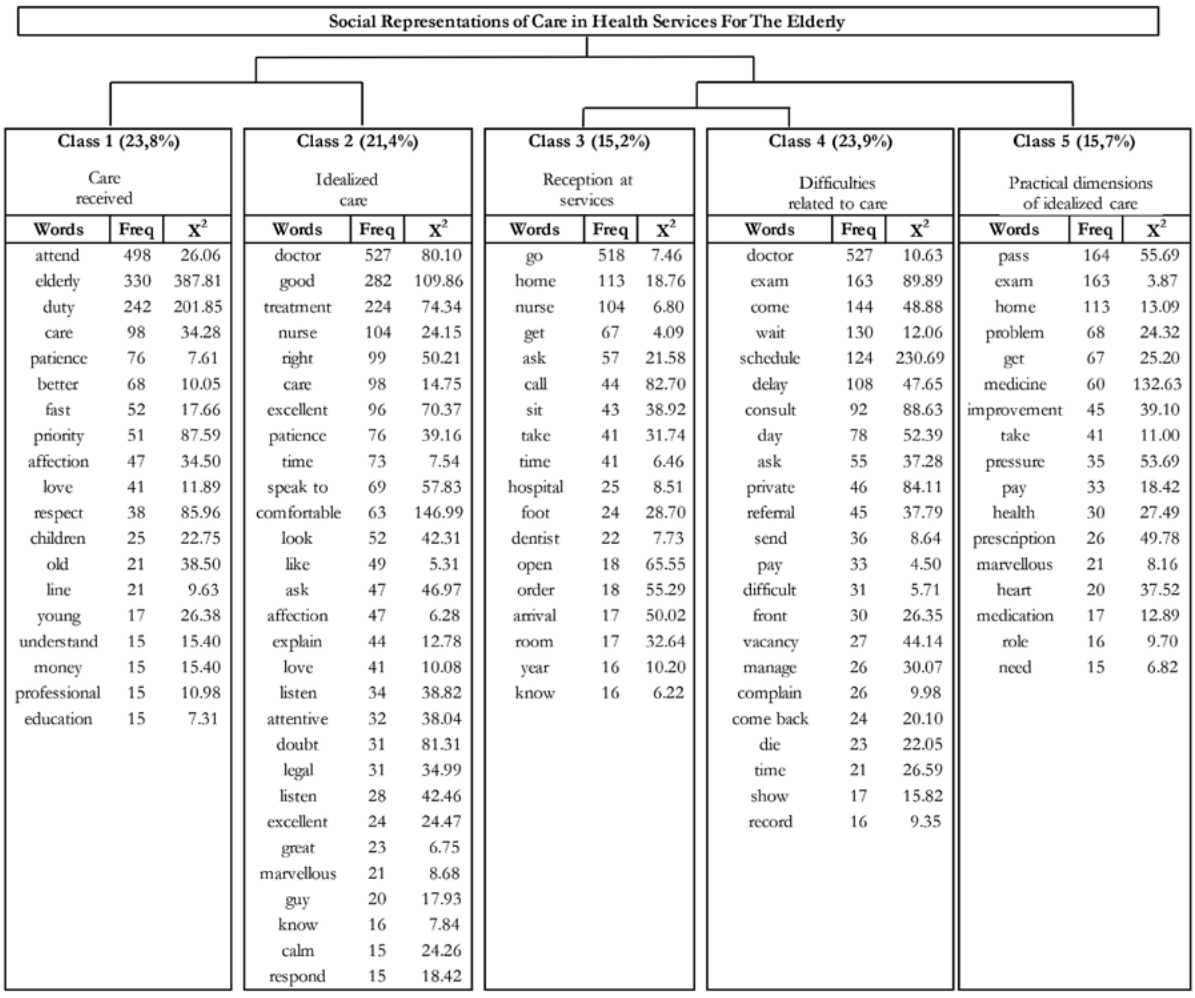
Among the elderly people interviewed, most were aged between 60 and 69 years old (45.4% of the sample), were female (74.8%), had a primary level education (56.3%) and were married (42.0%), with a family income of two Brazilian minimum wages (MWs) or more (76.4%) (Table 1).

In terms of the analysis of the corpus by IRaMuTeQ, 1240 Text Segments (TS) were retained, corresponding to 94.44% of the 1313 TS of this study. Through DHC, the social representations of the level of service provided by the health services for elderly people were separated into five semantic classes, established based on their content. The program also identified the intersection and description of the classes (DHC) and created the dendogram of the classes of the corpus, as shown in Figure 1.

Table 1. Social and demographic characteristics of the elderly people interviewed at the Family Health Units (FHUs) and at the Center for Integral Healthcare for the Elderly. João Pessoa, Paraíba, 2016.

Variables	n	%
Age		
60 to 69 ages	54	45.4
70 to 79 ages	50	42.0
80 or over ages	15	12.6
Gender		
Female	89	74.8
Male	30	25.2
Schooling		
Illiterate	14	11.8
Can read and write	3	2.5
Primary Education	67	56.3
High School Education	24	20.2
Higher education	11	9.2
Marital Status		
Married	50	42.0
Single	14	11.7
Widowed	44	37.0
Divorced	7	5.9
Separated	4	3.4
Family Income		
<one minimum wage	4	3.4
One minimum wage*	24	20.2
Two minimum wageor more	91	76.4

* The value of the minimum wage considered in the year of the research was equivalent to BRL 880.00.



Class 1 (23,8%) — Care received

Words	Freq	X^2
attend	498	26.06
elderly	330	387.81
duty	242	201.85
care	98	34.28
patience	76	7.61
better	68	10.05
fast	52	17.66
priority	51	87.59
affection	47	34.50
love	41	11.89
respect	38	85.96
children	25	22.75
old	21	38.50
line	21	9.63
young	17	26.38
understand	15	15.40
money	15	15.40
professional	15	10.98
education	15	7.31

Class 2 (21,4%) — Idealized care

Words	Freq	X^2
doctor	527	80.10
good	282	109.86
treatment	224	74.34
nurse	104	24.15
right	99	50.21
care	98	14.75
excellent	96	70.37
patience	76	39.16
time	73	7.54
speak to	69	57.83
comfortable	63	146.99
look	52	42.31
like	49	5.31
ask	47	46.97
affection	47	6.28
explain	44	12.78
love	41	10.08
listen	34	38.82
attentive	32	38.04
doubt	31	81.31
legal	31	34.99
listen	28	42.46
excellent	24	24.47
great	23	6.75
marvellous	21	8.68
guy	20	17.93
know	16	7.84
calm	15	24.26
respond	15	18.42

Class 3 (15,2%) — Reception at services

Words	Freq	X^2
go	518	7.46
home	113	18.76
nurse	104	6.80
get	67	4.09
ask	57	21.58
call	44	82.70
sit	43	38.92
take	41	31.74
time	41	6.46
hospital	25	8.51
foot	24	28.70
dentist	22	7.73
open	18	65.55
order	18	55.29
arrival	17	50.02
room	17	32.64
year	16	10.20
know	16	6.22

Class 4 (23,9%) — Difficulties related to care

Words	Freq	X^2
doctor	527	10.63
exam	163	89.89
come	144	48.88
wait	130	12.06
schedule	124	230.69
delay	108	47.65
consult	92	88.63
day	78	52.39
ask	55	37.28
private	46	84.11
referral	45	37.79
send	36	8.64
pay	33	4.50
difficult	31	5.71
front	30	26.35
vacancy	27	44.14
manage	26	30.07
complain	26	9.98
come back	24	20.10
die	23	22.05
time	21	26.59
show	17	15.82
record	16	9.35

Class 5 (15,7%) — Practical dimensions of idealized care

Words	Freq	X^2
pass	164	55.69
exam	163	3.87
home	113	13.09
problem	68	24.32
get	67	25.20
medicine	60	132.63
improvement	45	39.10
take	41	11.00
pressure	35	53.69
pay	33	18.42
health	30	27.49
prescription	26	49.78
marvellous	21	8.16
heart	20	37.52
medication	17	12.89
role	16	9.70
need	15	6.82

Figure 1. Dendogram of classes of social representations of services provided at health services for elderly people.

As Figure 1 shows, the software divided the classes into two main groups: one group was divided into two classes (1 and 2) and the other into one (5) which was in turn divided into two further classes (3 and 4). The first group (Classes 1 and 2) deals with affective aspects related to the services provided and, individually, each class presents one of the largest concentrations of TS of the whole corpus. The second group, represented by Class 5, deals with practical aspects about the ideal form the elderly people feel the services provided should take. This was divided into two further classes, which shows how the services occur in reality, including current difficulties. Class 4 also has one of the highest proportions of TS, together with Classes 1 and 2.

To draw and construct the dendogram, the words with a chi-square (χ^2) value of 3.84 or over ($p<0.001$) and frequency within classes of 14.45 or over, were selected. This cut-off point was established using the IRaMuTeQ software.

DISCUSSION

Among the elderly people interviewed, there was a prevalence of women, with a low income and poor level of schooling. The classes were established based on Social Representations Theory and current literature and are described below.

Class 1 –Service Received

In general, the interviewees reported that they were well attended to and treated, and this concept was linked to that of talking, explaining, showing interest in the patient's health problems and their personal life, being attentive, being polite, and knowing how to listen:

> "The health professionals are very attentive. They ask question, explain things, and resolve our concerns […]" (Subject 11).

> "I like this health professional a lot because they are attentive, polite, educated, and treat patients with loving care […]" (Subject 150).

It was also confirmed that good service results in the common idea that the elderly have of these professionals, namely that they are mothers, angels, friends, family members, establishing bonds between them:

> "This health professional is a real angel [...]" (Subject 43).

> "It is good, as we become a real family out here. They know our names, they know everything about us, the environment is like a real family […]" (Subject 51)

> "This health professional is my friend[...]" (Subject 65).

> "This health professional is like a mother[...]"(Subject 144).

The relationship between health professional and user is beneficial to the extent that it establishes a relationship of bonding and trust, leading to greater participation in the actions for the promotion of health and prevention of health problems[8].

Class 2 – Idealized Service

When asked about how they should be attended to when seeking out health services, the answers tend to show emotional aspects:

> "Elderly people need a lot of love and attention. People need to have a lot of patience [...]" (Subject 29).

> "Elderly people should be attended to with respect, patience, priority, love and understanding[...]"(Subject 51).

With advancing age, the thought of imminent death, the lack of social support through the loss of a partner, the departure of children from the home, or a lack of attention from relatives, even though the elderly people may still live with their families could all lead to greater emotional fragility in the elderly person[9].

Other aspects mentioned by elderly people refer to the need to be treated quickly and given priority:

> "An elderly person should be seen to quickly and get very good service. Elderly people shouldn't have to wait [...]"(Subject 138).

> "I should be attended to first. Elderly people should have priority, but that doesn't happen here[...]"(Subject 32).

The Law of the Elderly made a significant contribution to the defense of the rights of the elderly person. One of these rights is to priority treatment at Government institutes and private companies, which is not observed in many cases. However, when considering care priorities within health services, another factor to be borne in mind is the seriousness of the condition (and the overall need) of the user at the time[10].

The service should take the needs of the elderly person into account:

> "It's important to try to find out what their needs are. If it's medicine, or treatment, or something else. Often the proper attention isn't paid to the elderly person. [...]"(Subject 7).

Many of these needs are linked to the idea that the interviewees have about the elderly, namely that they are frail, ill, and about to die[11]. Some respondents compare elderly people with children, due to their general state of frailty and dependence, and also

because they are largely ignored and discriminated against by society in general.

The needs described as essential for people of advanced age, may also differ from those identified by the health professionals, which can affect adherence to the treatment established[12]. When their demands are not considered, and when there are barriers blocking access to, or the use of, services, there can be a greater distance between the services and the elderly people, as well as the non-accompaniment, by the health team, of the overall changes linked to the aging process, making them more prone to health risks (and other risks) and also to complications of the chronic diseases as already present[13].

Many of the interviewees have chronic diseases (high blood pressure, cardiopathies, diabetes, arthrosis), which bring serious functional limitations which make it more difficult to get to the health services, and also making it difficult to remain seated, or stand up, for a long time. Some also take care of family members, which not only makes it more difficult for the patient to get to their health appointments, but also makes them distressed, due to the delays in receiving care.

Home visits, as established in the Family Health Program (FHP), benefit, first and foremost, elderly people who are unable to get to the health units, and who would be excluded from care. However, elderly people complain that such visits do not happen often enough:

> "[...]She only comes to the house a few times[...]"(Subject 22).

> "[...]When the elderly person is bedridden, there should be more visits[...]"(Subject 43).

The health professionals also report many difficulties in relation to home visits, such as an insufficient number of health professionals, a lack of transport, and problems reaching the most outlying areas, which has also been detected by a study carried out in Rio de Janeiro[14].

Class 3 – Reception at Services

The reception recommended by the Brazilian Ministry of Health involves moments of listening to and displaying empathy and interest in the patient, and the identification of the social, psychological and biological needs of users, while following the principle of equity[15]. However, the perception of reception of many professional staff and students at the services is largely related to a bureaucratic service: Welcoming the users and then sending them elsewhere for treatment. They are often inflexible and do not take the needs of the clients into consideration[16].

At the FHU surveyed, it was observed that the reception process is carried out by employees at the reception desks and also by Community Health Agents (CHA) who end up deciding who has priority of treatment. Normally the elderly people end up getting priority, but more urgent cases may be overlooked, and the individual advised to return another day, or even to seek alternative services, due to the lack of evaluation by a better qualified health professional. The Ministry of Health recommends that reception should be carried out by a nurse who, after listening to the needs of the user, can carry out interventions based on their own abilities or refer the patient on to other health professionals[17].

At CAISI, consultations with health professionals are booked in advance at the FHU. When the patients arrive at the location, they wait their turn to be seen:

> "It's on a first come, first served basis. You need to get there first, and then give your name. [...]"(Subject 46).

> "We arrive, sit on the chairs, then we ask the attendants for a form, and then they start calling out the names[...]" (Subject 123).

The users normally arrive early in the morning, so they can be one of the first to be served. If not they may end up not getting an appointment, in the

case of the FHU. This reality was also reported in a survey carried out in the city of Rio de Janeiro (RJ)[18]. One of the main complaints of elderly people relates to the lack of punctuality of the health professionals:

> "I have waited up to five hours to be seen. The health professional books a time, and then arrives at a different time. We can waste a whole day here[...]"(Subject 226).

Class 4 – Difficulties related to service

The number of people attended to in the assessed services is limited. If the doctor orders an appointment with a specialist, or further diagnostic examinations, then the wait for medical care continues. Due to the limited number of time slots to book such procedures, many users have to wait months before they can be seen by a doctor.

Some elderly people even resort to private health services, sacrificing their pensions, and even request the help of family or friends, some even sell assets or take out loans with financial institutions to pay for medical examinations and appointments, so they do not need to wait to be attended to by the Government health system:

> "I would rather pay for a private appointment than go to the FHP. Sometimes the medical professional doesn't turn up. When the medical professional does show up, then we can't a place. You put your name down, and it is often two or three months before we are referred[...]"(Subject 166).

Others mention the inefficiency of the system for scheduling appointments and medical examinations, or just a lack of care. In cases like this, the employees themselves advise the elderly people to seek private medical services:

> "I went to book my transvaginal ultrasound. They said there were no places, and that I should get it done privately […] (Subject 220).

A discussion of the real need to request these examinations is outside the scope of this paper. However, there are studies that warn about the indiscriminate practice of recommending medication and medical tests, pandering to the medical-industrial complex, and also referrals to specialists for individuals with health problems that could be handled by basic health care. This makes it difficult for those patients who truly require this technology to access it, and also presents an additional cost burden for the health system[19]. In addition, the scheduling of referrals to more complex services should consider the health needs of the user, rather than the order of request[20].

Primary Health Care is the entry-point to the health system, to ensure greater efficiency and savings, and its importance is recognized by many healthcare managers who, in practice, are unable to implement it. At the same time, it is undervalued by the population who use the health system. Some possible causes for this are low resolutive capacity, political and financial prioritization of specialist care; lack of general practitioners; and the opening hours of the basic health units that do not consider the needs of their users[21].

As PHC cannot function asa coordinator of care and a provider of solutions for the demands of elderly health care, such issues must be resolved in another form, disregarding the structure of the PHC as established by national guidelines for the implementation of the National Health Care Network. One of the ways in which we can impart greater legitimacy upon Basic Health Care (BHC) in relation to its users is to give greater independence to this level of care, thereby increasing its capacity to effectively manage regulatory processes, allowing health teams to gain direct access to the booking of medical appointments, and allowing doctors to have better communication with regulatory bodies, whenever necessary[22].

Another issue to be addressed is the scheduling of the FHU service based on days for particular health issues or population groups. It is important that the treatment provided to priority groups for health care, as established by the MH (children, pregnant women, hypertensive patients, and people living with diabetes), is not morphed into actions that limit the access of other users to services[23]. The elderly people complain about the delay and lack of

service at the FHUs, as they do not fit into such a schedule of needs. This situation was also described in a study carried out in the state of São Paulo[24]:

> "They say today is the day for pregnant women, so they cannot attend to us. On the day for pregnant women, only they get seen[...]" (Subject 130).

Some elderly people confess that they resort to the use of family members and friends who are in some way linked to the services, in the hope of getting quicker treatment:

> "As my son works here, I am seen to quickly[...]"(Subject 215).

> "I only managed to book my bone densitometry because I have a friend who works at theFHP[...]" (Subject 250).

> "It took me six months to have a medical examination. I spoke to the health professional, who said that in January I would be the first patient to be seen to[...]"(Subject 57).

In addition to all these difficulties, in many cases elderly people are sent to units far from their homes, requiring them to use public transport. This, apart from adding extra expense, may also cause an excessive physical burden. Many are referred from one place to another:

> "You live in one district and near your home there is a laboratory that serves the area; however, they send you somewhere else, and you often have to take a bus. For medical appointments, they normally send you very far away [...]"(Subject 202).

> "When I arrived, the health professional sent me to Tambaú for a tooth implant. When I got there, she wasn't there. On another day, the equipment was broken and they asked me to come back another day. So I came back, and there was no professional available. I never went back [...]" (Subject 3).

The choice of the referral service should bear the specific needs of the users in mind. This would include factors such as functional, cognitive, and financial limitations, which make travel difficult. One must also consider whether these people have the means to access these locations, especially in the case of elderly people. This could be achieved, for example, through a search for service providers closer to the patient's residence and also an investigation of social networks of the elderly, to see if there is anyone who could take responsibility for accompanying them.

According to the employees of the FHUs studied, the choice of the referral service is only based on availability of places, regardless of location. This is because, if it were not performed in this way, access to medical care would be even more at risk, due to the reduced number of vacancies compared to the demand.

For booking medical appointments and diagnostic examinations, the National Regulation System (or SISREG) is used. This is an online system (employing a specific software system) that manages specialized outpatient and hospital resources at municipal, state and regional level. This computerized system has brought many benefits, including avoiding unnecessary travel to specialized services for booking appointments, as everything can be done online[25].

However, some authors have described difficulties in using this system, which can help us understand some of the problems reported by the elderly in this study, including: absence of an access protocol number for services, definition of when the medical procedure is routine, priority, or urgent; inability of operator to use the system, leading to mistakes when filling in the requests; technical problems related to the program and Internet connections; and lack of specialists in certain areas[26, 27].

A need to improve the information about the operation and function of the system itself has also been noted (a lack of signage in the treatment room and a shortage of information about the procedures necessary to obtain prescriptions and book appointments was observed) and also referrals to other services. Information should be passed to the elderly using audible and appropriate language. At the same time, one must identify hearing deficiencies and low levels of education.

One strategy to improve information, and to streamline and modernize service would be to make greater use of technology. Many developed countries deal with their users by telephone or e-mail. This is not a replacement for physical examination, but rather a way to provide guidance and answer queries. This also means that the user does need to go to the health unit just to find out whether their appointment has been arranged or if there is a doctor available to attend to the patient. In addition, the telephone can also be used by employees to remind the elderly patients about the dates and times of their appointments and examinations, which could reduce the rate of absenteeism and allow vacancies arising from cancellations to be properly utilized[28,29].

Another complaint described by the elderly people interviewed is the need to first go to the FHU when booking an appointment with a medical specialist, as this is a major obstacle to getting treatment, which was also observed in a study carried out in the state of São Paulo[30], or for a simple bureaucratic procedure to receive prescriptions for medication and referrals to specialist doctors, or to register whether treatment has been carried out:

> "After entering the FHP, you go to the general practitioner, who books a time, and then you hand the time scheduled to the official appointment scheduler. One month, two months, three months, even a year. Anyone with a serious condition may die without even being attended to. The problem lies mainly with the FHP [...]"(Subject 125).

> "Is it the prescription you want? They ask what the medication is, and that's all. They don't even give you attention, they couldn't care less. I just come to pick up my prescription […] (Subject 30)

> "On Friday I go to the FHPhealth professional to ask for a referral to the cardiologist [...]"(Subject 109).

The negative perception of elderly people with regard to the FHU is based on the lack of resolutive capacity of these services, due to difficulties of access to different levels of care, which breeds a lack of satisfaction and a lack of credibility in relation to the service, and therefore of the health service as a whole[31].

Class 5 –Idealized practical dimensions of the service

The interviewees highlight the characteristics of the services provided, which are considered as representations, anchored to a doctor-centric culture, medicalization, and the compartmentalization of health services into specialities[32]:

> "Good service is requesting medical exams, and giving medication[...]" (Subject 217).

> "I like it here because we have the specialties. There was a health professional who was good, and has now been transferred. The medication that he gave to me[...]"(Subject 131).

This is due to the biomedical model for health care, to which the population has been submitted, and which remains in the imaginary of users and also the practice of many health professionals, making its deconstruction extremely difficult[33]. The value given to health care based on specialized care is evident in some statements:

> "The general practitioner (GP) needs to know a lot. You go to the urologist, it is for one specific thing. The same goes for the eye doctor, and the head doctor. Now, the general practitioner is for everything[...]" (Subject 3).

> "To improve the service, we need specialists. In the past we had everything here, even heart specialists, it was really great. Now they have taken everything away, and put this other service in [...]"(Subject 131).

Another study carried out in Brazil showed the lack of recognition of Primary Health Care professionals, especially doctors, by the users. The training of these professionals should be one of the top priorities of the Government, because it increases the credibility of the population, who then have more trust in these services and their capacity to solve health problems[34].

One limitation of the present study was the fact that it was carried out in health services in only one Brazilian municipal region, however, the results found

reflect many of the problems with health services experienced by people in other parts of Brazil and in other countries with Universal Health Services, which feature primary health care as the basis of their health systems, as described throughout the article. Another limitation is that the perception of the users may have been influenced by their own social and economic context, the context within which the services are located, and the type of service received and expected (basic health care or specialized health care).

The fact that the interviews took place in the same location as treatment was received could also be a significant limitation. However, it was observed that most of the interviewees were willing to talk about the health care received, and the difficulties that they face (only 20 elderly people refused to participate in the survey), and considered the interviews as a place where they can speak and be heard. What may have contributed to this was the assurances provided regarding their confidentiality of their identity, the fact that the survey took place in a closed room (with only the elderly interviewee and the interviewer present), and the fact that it was carried out by a person unattached to the services[35].

CONCLUSION

The study describes, as social representations, the fact that the elderly people associated good health care with being treated with respect, attention and politeness. In their opinion, health professionals should talk, explain, and show interest in their health problems and personal life. At the same time, they connected good service with the prescription of medication and medical tests, along with referrals to specialists, which reinforces the culture of giving greater value to the biomedical model of health care.

In the imaginary of those interviewed, the FHU represents more of an obstacle than a gateway to entering the health care system, as it hinders the obtaining of specialized health care. In addition to this meaning, which is often assigned to the FHU, there is the perception that the basic health care doctor does not have the knowledge to simultaneously deal with people from different age brackets and with different health problems, meaning that an appointment with a specialist is required.

In the locations surveyed, elderly people exhibited satisfaction with the care and service they received, at least with regard to the affective relationship with the staff. They all felt welcomed and well treated. At the same time, they complained about many aspects that need to be reviewed and improved, some specifically concerning the dynamics of the locations investigated, and others related to the function of the health system in general. Regardless of whether these problems are related to the system or the service, the solution to these problems must consider the Humanization Policy of the Brazilian Ministry of Health and also the International Protocols for User Care, especially those related to elderly people (*Towards Age-friendly Primary Health Care*).

It is also important to stress that the purpose of this study was not to specifically evaluate the health services studied, or even to assess the health professionals working there. These individuals should also be heard, to investigate the possible difficulties they face, which could result in further user dissatisfaction. In any case, it is hoped that these results contribute to modifying the viewpoint and practice of health professionals and managers, with regard to the services offered to elderly people, considering the specific characteristics of this age group, so that they may have a better chance of having their health problems resolved.

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Prescription of potentially inappropriate medication for the elderly: comparing health service providers

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Abstract

Objective: to compare the prescription of medications to elderly users of the SUS with users of a Supplementary Health Plan in the context of the Beers criteria. *Method*: a quantitative documental analysis using two databases, obtained from surveys conducted in the same municipal region, was performed. In the first database, the sample included 532 people aged 60 years or older, of both genders, who were users of the SUS. In the second, the sample was 239 people aged 60 years or older, irrespective of gender, who were users of the principal supplementary health plan. Statistical analyses to compare the data of the two databases were performed using Pearson's Chi-squared Test and the extension of Fisher's Exact test, with a significance level α equal to 5%. *Results:* The results showed significant differences in the use of medications and polypharmacy among the users of the two service providers. Moreover, there were statistically significant differences between the service providers, with SUS users using more non-steroidal anti-inflammatory drugs (p=0.01), long-lasting sulfonylureas (p=0.02) and Nifedipine (p=0.01), and the users of the Supplementary Health Care plan using more musculoskeletal relaxants (p=0.01), estrogen (p=0.01), amiodarone (p=0.01) and Doxazosin (p=0.01), which are potentially inappropriate for the elderly. *Conclusion*: there are differences between having health insurance or not in terms of the profile of drug use, including in medications which are potentially inappropriate for use among the elderly. The use of information technology that centralizes the data of the elderly, both in the SUS and in Supplementary Health, could reduce inappropriate or unnecessary prescriptions.

Keywords: Supplemental Health. Unified Health System.Health of the Elderly. Drug Utilization. Polypharmacy.

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INTRODUCTION

Health policy in Brazil has been established in a segmented manner since the outset. Even though the 1988 Brazilian Constitution made access to health services universal for Brazilian citizens, difficulties in the implementation of this policy have resulted in the development of a market for private health services[1]. Between 2012 and 2018 in Brazil there was an 18.8% growth of people aged 60 years or over whose health care needs were met both by the public network, free of charge and of universal access, and private health plans, with access limited to the coverage subscribed to and also by the income of the client[2]. Data from the Brazilian Agency for Supplementary Health Services show that the age pyramid of the population that benefit from health plans has a slightly older profile than that of the population without any private health plans, with elderly people accounting for 12.0% of the population with health plans and 10.0% of those without such plans[3].

Elderly people make up a segment of the population with a high occurrence of morbidities and, as a result, are subject to the use of polymedication[4]. As homoeostatic responses are nearly always important components of the overall response to a certain type of medication, the physiological changes which occur among the elderly may indeed alter the standard or the intensity of the response to this medication, which may even play a part in its toxicity[5]. The problems most commonly found when applying medication to elderly people are the use of the incorrect medication, the wrong dose, taking medication at incorrect intervals; taking medication for too long or for not long enough; and also inappropriate combinations with other pharmaceuticals, causing undesired interactions[6].

As part of health care for the elderly, primary health care is the main gateway to health care services in the Unified Health System (or SUS). Its actions are aimed at interdisciplinarity and also the sharing of medical services to the user, through e-SUS, a national electronic database of medical files, a resource which is still being implemented by municipal regions[7].

Another way of providing care to the elderly is through private health plans that essentially provide fragmented services which, in most cases, do not include specificities, basing themselves on hyper-specialization and lack of integral treatment, without a computerized system for the annotation and registration of health care. This situation may also lead the elderly person to the irrational use of medication, not always paying attention to the distinctive characteristics of the pharmacotherapy used by this population or their pharmacological history.[8]

Thus, for the rational use of medication to occur, a series of complex requirements should be followed, with the participation of social players such as patients, health professionals, legislators, public policy planners, and also industrial companies, commercial firms, and the government.

Seeking a better understanding of the reality of the prescription of medication for elderly people in the Brazilian private and public health systems, the main purpose of this study was to compare the medical prescriptions of elderly people who use the public health system (or SUS) with users of Supplementary Health Plans, based on the updated Beers criteria[9]. These criteria are the most commonly used in the Americas to evaluate potentially inappropriate medication, and can be divided into three categories: those which are potentially inappropriate and which should not be given to elderly patients; those which are potentially inappropriate and which should not be used for elderly people with certain illnesses; and those which should be used with care in elderly patients.

METHOD

The present study was based on documental analysis, and adopted a quantitative approach, in which associations between social and demographic data and data regarding the consumption of prescribed medication were analyzed, focusing on elderly people using the SUS medical system[10] and on those using Supplementary Health plans[11], in a municipal region in the midwest of the state of São Paulo, Brazil.

According to the Brazilian Institute of Geography and Statistics (or IBGE), in 2018, the municipal region had an estimated population of 237,000 people, of whom around 13.0% were elderly. Elderly

people with supplementary health plans account for 34.7% of the total population, and 15.4% of these are 60 years old or over[3].

Data from two studies previously performed in the same municipal region was used[10,11]. The DIMAM 1.0 program was used to establish the sample size of both studies, which bases its findings on the population and the prevalence of the use of medication (80.0%), considering a margin of error of 5% and a confidence level of 95%, thus ensuring representativity. The first study was based on a population of 29,124 elderly people, resulting in a group of 532 people, aged 60 and over, regardless of gender, who were neither hospitalized nor in care facilities, who were users of the SUS services and who lived in areas within the catchment areas of the Family Health Strategy (or ESF) and Basic Traditional Health Units (or UBST)[10]. The second study was based on a universe of 8,474 elderly people, users of supplementary health plans, and produced a subgroup of 239 people, regardless of gender, who neither hospitalized nor in care facilities[11].

Data for both these studies was collected through home interviews, performed directly with the elderly people who were capable of communicating, using the same standardized and semi-structured questionnaire. The first study took place between August and November 2012, and the second between May 2014 and January 2015.

The two studies evaluated social, economic, and demographic variables and also health indicators: gender, age (grouped in age groups of 60 to 69, 70 to 79, 80 or over years), level of schooling (up to four years of schooling; five years or more of schooling), income, household status and self-assessment of health, obtained from responses to the question: "How would you rate your current state of health?" The self-assessment of health situation was evaluated on a scale including the variables: excellent, good, fair, poor, or very poor. For statistical purposes, the answers of fair, good and excellent were considered a positive self-assessment. Similarly, the answers 'poor' and 'very poor' were considered as negative self-assessment[12].

With regard to consumption of medication, the interviewer asked the elderly people to bring all the medication that they had used in the 15 days immediately preceding the collection of data, allowing the verification of quantities and also the establishing, in both databases, of those that were potentially inappropriate, through a review of the Beers criteria[9], which identified 53 medications, or classes of medications, as unsuitable for use with elderly patients, regardless of diagnosis and general conditions[9]. This review was used for the analysis of both databases.

The statistical analyses relative to the comparison between the data of both these databases were performed by using the Statistical Package for the Social Sciences (SPSS) software program, version 17.0 for Windows. All variables were shown as absolute and relative frequencies. For comparative analysis, the independent variable was the type of service provider, and the dependent variables were data on the consumption of medication. The Chi-Squared (χ^2) and Fisher's Exact tests were used to check the existence of important differences between the variables. Relations between variables where $p \leq 0.05$ were considered statistically significant.

This study was approved by the Ethics Committee for Research Involving Human Subjects, of the Faculdade de Medicina de Marília (Marília, São Paulo, Brazil) under opinion statement No. 1.557.759. As this study is based on documentary analysis, the need for a Free and Informed Consent Form (FICF) was waived. The obtaining of data from the databases used was approved by the same Ethics Committee, based on Opinion Statements Nº. 799/10 dated November 29, 2010[10] and Nº. 607,824 dated 31/03/2014[11], and the acquiescence of the respective participants of both was obtained through the signing of the respective FICFs.

RESULTS

The social and demographic data reveal a greater number of women than men, for both service providers; the predominance of elderly SUS users in the age bracket between 60 and 69 years old and of elderly users of supplementary health schemes in the 70-79 age bracket; most of the SUS users had up to four years of schooling, while in the case of supplementary health plans most users had five years

of schooling or more. The other variables show, for both service providers, the predominance of incomes of between one and three minimum wages (MWs), people who live with others, and positive self-evaluations of health (Table 1).

Table 2 shows that there is a difference in the use of medication between SUS and Supplementary Health users, with a greater prevalence in Supplementary Health Care (p<0.01). There was also a difference between the two providers in terms of quantities used: the use of five or more types of medication was more common among Supplementary Health users. (p<0.01).

Table 3 shows that there was a statistically significant difference between the use of PIM among SUS and Supplementary Health users, for medications of the Musculoskeletal, Endocrine and Cardiovascular systems, as defined by the Beers Criteria. With regard to the Musculoskeletal System, there was a prevalence of non-steroidal anti-inflammatory drugs (NSAIDs) in the case of SUS users, and muscle relaxation drugs for people with supplementary health plans. For the endocrine system, the two groups used insulin the most. However, there was a predominance of long-duration Sulfonylureas use in the SUS, and Estrogen in supplementary health care. With regards to the cardiovascular system, there was a prevalence of Nifedipine among SUS users, and of Amiodarone and Doxazosin among supplementary health care users. Antimicrobial and Antithrombotic drugs were only used by supplementary health care users, while Antispasmodics and Analgesics were used by SUS users.

Table 1. Social, demographic and economic data for elderly users of SUS and supplementary health plans. Marília, São Paulo, 2017.

Variables	SUS	Supplementary Health Care	p*
	n(%)	n(%)	
Gender			
Male	202(38.0)	50(20.9)	0.01
Female	330(62.0)	189(79.1)	
Age			
60-69	249(46.8)	90(37.7)	0.02
70-79	202(37.9)	91(38.1)	0.98
80 +	81(15.3)	58(24.3)	0.01
Schooling			
Up to four years of study	446(83.8)	59(24.7)	0.01
Five or more years of study	86(16.2)	180(75.3)	
Income in minimum wages			
<1	15(2.8)	23(9.6)	0.01
1 to < 3	386(72.6)	117(48.9)	0.01
3 to < 5	79(14.8)	64(26.7)	0.01
5 to 10	39(7.3)	28(11.7)	0.04
Don't know / Declined to answer	13(2.4)	7(2.9)	0.69
Household Status			
Live alone	60(1.3)	58(24.3)	0.01
With others	472(88.7)	181(75.7)	
Self-assessment of health			
Negative	45(8.4)	6(2.5)	0.01
Positive	433(81.4)	233(9.5)	0.01
Declined to answer	54(10.2)	0(0)	0.01

* $p \leq 0.05$ – Chi-Squared test

Table 2. Use of medication in the 15 days prior to the collection of data from elderly SUS and Supplementary Health users. Marília, São Paulo, Brazil, 2017.

Variables	SUS	Supplementary Health Care	*p**
	n(%)	n(%)	
Use of Medication			
Yes	475(89.3)	232(97.1)	0.01
No	57(1.7)	7(2.9)	
Number of types			
1 to 4	262(55.2)	82(35.3)	0.01
5 or more	213(44.8)	150(64.7)	

* $p \leq 0.05$ – Chi-Squared test

Table 3. Potentially inappropriate medication for the elderly, regardless of pathology of SUS and Supplementary Health users, according to the Beers criteria, 2015. Marília, São Paulo, Brazil, 2017.

Group/Medications	SUS n(%)	Supplementary Health Care n(%)	*p**
Musculoskeletal System			
Musculoskeletal relaxation drugs	8(23.6)	43(79.6)	0.01
Non-steroidal Anti-inflammatory drugs	26(76.4)	11(20.4)	
Total	34(100)	54(100)	
Gastrointestinal			
Protein Pump Inhibitors	68(95.8)	35(97.2)	0.59
Metoclopramide	3(4.2)	1(2.8)	
Total	71(100)	36(100)	
Central Nervous System - CNS			
Benzodiazepines	36(41.9)	17(47.2)	0.58
Amitriptyline	25(29.1)	8(22.2)	0.44
Paroxetine	2(2.3)	4(11.1)	0.07
Phenobarbital	2(2.3)	3(8.3)	0.15
Non-benzodiazepine hypnotic agents	0(0)	1(2.8)	0.29
Imipramine	4(4.6)	0(0)	0.24
Nortriptyline	2(2.3)	2(5.6)	0.34
Haloperidol	3(3.5)	0(0)	0.35
Chlorpromazine	1(1.1)	1(2.8)	0.51
Cimetidine	5(5.8)	0(0)	0.17
Ranitidine	6(6.9)	0(0)	0.12
Total	86(100)	36(100)	
Endocrine			
Insulin	23(50.0)	9(56.2)	0.67
Estrogen	2(4.4)	5(31.2)	0.01
Long-duration sulfonylureas	21(45.6)	2(12.5)	0.02
Total	46(100)	16(100)	

to be continued

Continuation of Table 3

Group/Medications	SUS n(%)	Supplementary Health Care n(%)	*p**
Cardiovascular			
Amiodarone	0(0)	9(12.9)	0.01
Nifedipine	38(32.8)	2(2.9)	0.01
Digoxin	8(6.9)	2(2.9)	0.20
Methyldopa	2(1.7)	1(1.4)	0.68
Clonidine	1(0.9)	0(0)	0.62
Doxazosin	6(5.2)	14(20.0)	0.01
Diltiazem	1(0.9)	1(1.4)	0.61
Cilostazol	6(5.2)	0(0)	0.06
Acetyl salicylic acid	54(46.6)	41(58.6)	0.12
Total	116(100)	70(100)	
Antimicrobial			
Nitrofurantoin	0(0)	3(100)	
Antithrombotics			
Ticlopidine	0(0)	2(100)	
Anticholinergics			
Hydroxyzine	2(20.0)	1(100)	0.27
Dexchlorpheniramine	4(40.0)	0(0)	0.64
Promethazine	4(40.0)	0(0)	0.64
Total	10(100)	1(100)	
Antispasmodics			
Scopolamine	8(100)	0(0)	
Painkillers			
Meloxicam	7(100)	0(0)	
Insomnia			
Caffeine	7(100)	25(100)	
Overall Total	385	243	

*$p \leq 0.05$ – Chi-Squared Test

DISCUSSION

The female gender prevailed in both groups. These data are similar to those found in another study carried out with SUS users in the city of Petropolis, near Rio de Janeiro, where most of those interviewed were women[13], and also the results obtained by a study with elderly people with supplementary health plans, where 65% of the sample were women[8]. In Brazil, women tend to live longer than men, meaning that old age has become more of a feminine phenomenon[14]. This is an aspect to be considered for health care services, as women have more complex health problems than men of the same age.

With regard to age, it should be remembered that, the more advanced an individual's age, the greater the possibility of developing illnesses and the use of multiple types of medication, while social and economic conditions and lifestyle also warrant investigation, to evaluate the deterioration in health suffered by people of more advanced age[15].

Schooling and income have a major impact on the health situation of the population. Elderly people with more schooling and greater income are more independent in self-care, including the correct use of medication, means of transport and communication, while elderly people with lower spending power and/

or intellectual capabilities, are more susceptible to diseases and, as a result, require more health care[16], especially from public institutions, making this population highly dependent on the SUS.

There was a prevalence of incomes of between one and three minimum wages (MWs) among users of both health service providers, characterizing a low income population faced with increasing health costs arising from the ageing process and the increased occurrence of chronic diseases, as is the case in Brazil. For SUS users, this data is similar to that found in specialized literature[17].

Regarding family coexistence, most SUS users live with other people, while most users of supplementary health plans live alone. This result is the opposite of the results of a study based in Florianópolis, Santa Catarina, which found that 99.4% of elderly people, users of supplementary health care, lived with others (children, wives, other family members or caregivers)[18]. This variable is most likely linked to the culture and quality of regional life, with regard to security and crime rates, as well as other factors such as access to public transport, health services, pharmacies, food, and other such factors.

It is emphasized that family plays an important role in the provision of social and affective support for aging individuals, especially with regard to meeting the needs of the elderly person. Elderly people living alone are more prone to risks, and make less use of health services for preventative purposes, when compared to elderly people who live with their spouses and/or other family members[19].

When asked about their self-evaluation of health, there was a prevalence of individuals who gave a positive evaluation of their health among both SUS and Supplementary Health users. When the two groups were compared, however, SUS users were found to have a more negative self-evaluation. Elderly people with higher levels of positive affect tend to use constructive coping strategies when they are faced with challenges inherent to advanced age[20].

With regard to medication used in the last 15 days, the present study found results similar to those of specialized literature, both in relation to SUS users[21] as also to those who used supplemental health care. A study carried out in the southeast of Brazil found that 97.1% of elderly people with a health plan had taken some medication in the last 15 days[22], irrespective of the number taken. Even though polymedication is not limited to any particular age bracket, the elderly population is among the age groups that uses most medication and, therefore, generates higher costs for health systems, whether public or supplemental.

Use of medication is a reality among the elderly, and can be linked to several factors, such as the fact that ageing brings a higher possibility of prevalence of Non-Transmittable Chronic Disease (NTCD), especially among those who lead a sedentary lifestyle; the high medicalization of health, as observed in recent years and driven by the power of the pharmaceutical industry; the encouragement of the prescription of medication observed in the training and practice of health professionals; among others. Daily life becomes medicalized, as the individual gains familiarity with medical issues, and then considers health as a key asset and, as a result, does everything they can to preserve their health or quickly restore it, with low personal energy costs. This has resulted in the trivialization of the use of medication, both in Brazil and in other parts of the world[23].

In the present study, 64.7% of Supplementary Health users said they used five or more medications a day, which can be considered polymedication[24]. It should be considered that in many cases, such use is recommended for treating the many chronic diseases present among the elderly, aimed at survival and/or the improvement of quality of life. The use of five or more types of medication by most supplementary health users could be linked to the fact that they have more access to prescribers, usually from different medical specialities, which leads to an increase in prescription and the intake of medication. However, one must also qualify polymedication, so that the health of elderly people does not deteriorate[25], as a result of any undesirable effects or interactions.

With regard to SUS users, the work of an interdisciplinary team, often available on the Family Health Program, could play an important role in the assessment process, verifying whether the complaints have resulted from illness or whether they are simply adverse reactions to the use of medication. If they are adverse reactions, then the prescription and the

care given to the elderly patient can be changed, with the aim of observing the outcomes[26].

The prescription of potentially inappropriate medications for elderly patients (PIMs), according to Beers[9], is strongly linked to the triggering of adverse reactions to medication and hospitalizations and, when associated with the presence of comorbidities and polymedication, exposes elderly patients to a high risk of death. The presence of at least one inappropriate medication in a prescription doubles the risk of adverse reactions, which are responsible for some 24% of hospitalizations within this age group and which represent the fifth most common cause of death among elderly people[27-29].

In the present study, the presence of PIMs for use by the elderly was found in the following pharmacological groups: the musculoskeletal and gastrointestinal systems, the central nervous system (CNS), and the endocrine and cardiovascular systems, as well as antithrombotics, antimicrobials, anticholinergics, antispasmodics, painkillers, and medication to treat insomnia. Statistical analysis showed a significant difference between the variables and the type of service provider, for medication within the musculoskeletal, endocrine, and cardiovascular groups.

Regarding the use of PIMs, for the Musculoskeletal System, there was a predominance of NSAIDs (76.4%) among users of the SUS system, and of musculoskeletal relaxation drugs (79.6%) among people using supplementary health plans. The use of anti-inflammatory drugs among SUS users could be linked to the fact that this medication category is available at municipal pharmacies, unlike muscle relaxants, which are usually available at commercial pharmacies, and are often sold without presecription[3].

In the case of the endocrine system, the use of long-duration Sulfonylureas predominated among SUS users (45.6%), which are the only hypoglycemic drug on the list of standardized medications in the municipal region. This may also show that those who prescribe drugs within the SUS may not be familiar with the PIM criteria. Among users of supplementary health plans, there was prevalence of the use of Estrogen (31.2%), which could be linked to the fact that people using supplementary health services have greater access to specialists, and also because there are a few medications on the market that provide the effects of estradiol.

For the Cardiovascular System, the use of Amiodarone was only observed among users of supplementary health services. This medication, classified as an anti-arrhythmic drug, was the most prescribed within the group of cardiovascular drugs for elderly patients with national coverage supplementary health plans[8], and ranks among the main PIMs for cardiovascular use, in the Health, Well-Being and Ageing study (or SABE)[29]. Amiodarone is linked to many toxicities, including thyroid problems, prolonged QT interval, and lung disorders[9]. The risk-benefit relationship in dealing with arrhythmias must be evaluated and, when such drugs are recommended, they should be monitored with a view to preventing adverse effects or the early identification thereof[30]. It is also worth mentioning that, even though amiodarone is on the National List of Medications (or RENAME)[31], no elderly SUS user has ever been prescribed this drug.

Also within the cardiovascular system, SUS users used Nifedipine in greater proportions than patients using supplementary health services (p=0.01). The 'rapid action' formulation of nifedipine is considered inappropriate because, according to the Beers criteria, due to the potential risk of low blood pressure and constipation, these being the possible consequences of use considered most serious. Even though this drug is still commonly prescribed through the SUS, in the RENAME review[31], nifedipine was replaced by amlodipine as a dihydropyridine type calcium channel blocker, being recommended for angina of the chest, heart spasms, and high blood pressure[20]. Unfortunately, this medication is still not available at pharmacies at municipal health units.

Doxazosin, an alpha-blocker recommended for the treatment of systemic high blood pressure and benign prostatic hyperplasia, illnesses that often afflict the elderly, is used more often by the users of supplementary health services (p=0.01). Its main effects are vascular smooth muscle tone relaxation (vasodilation), which reduces peripheral vascular resistance, lowering blood pressure and also relaxing the bladder and prostate, making urination easier. Its use in elderly patients should be avoided, as

one of its side effects is a high potential for low blood pressure, dry mouth, and urinary alterations. However, as this is a frequently used medication and as it is recommended for cases of benign prostatic hyperplasia, it can be used with care, with monitoring and accompaniment as appropriate[32,33].

Many of the inappropriate medications for elderly patients are included in the RENAME, with the further concern that for certain therapeutic categories, the only standardized medication is considered inappropriate, according to Beers[9]. The criteria proposed by Beers and other research studies in scientific literature recommend that the risk-benefit ratio must be duly assessed before any medication is prescribed for elderly patients[34]. As this is a basic condition of Pharmacology, any prescribed medicine should be analyzed in this context before it is classified as incorrect or a medical error.

The publicizing of the concept of inappropriate use through continuous education; the inclusion of warnings on computerized prescription systems, the presence of a professional pharmacist for the dispensation of drugs and for guidance regarding their use, and clarifying the implementation of restrictive regulatory measures are all factors that would significantly facilitate the adoption of criteria that are not fully known to the entire medical community. These suggestions are considered essential for the prevention of potentially inappropriate medication[34].

Furthermore, the problem should be focused on the inappropriate prescription of these drugs; in other words, prescriptions made without due evaluation of the risks and benefits, which should guide anyone who prescribes drugs. For prescriptions to be correctly made, the prescriber must have appropriate knowledge of the risks associated with the medication, and he or she should make use of medications considered inappropriate only when there are no other options available, considering the health needs of the patient.

The link between the consumption of these drugs and disorders often ascribed to the aging process, with regard to pharmacokinetics and pharmacodynamics, results in conditions that bring a high risk of adverse effects and interaction between medications as observed in the elderly[34]. This means that a regular review of the medication used by the elderly should be an inherent part of clinical practice.

While the present study contributes data which indicates important necessities for the use of medication by elderly patients in both groups, a limitation is the fact that the reasons for the prescriptions have not been studied, which would provide a deeper analysis of the suitability of the medication used by the elderly. New studies that investigate other variables or even enhance the analysis of studies already performed are also recommended, when prescribing medication considered inappropriate for use by the elderly.

CONCLUSION

The consumption of medication in the 15 days leading up to the interview was confirmed in most cases, for the two groups analyzed. With regard to the quantity of medication used, there was a predominance of the use of between one and four types of medication for SUS users, and five or more types of medication for those using Supplementary Health, which amounts to polymedication in this group. These characteristics of Supplementary Health users could be associated with greater access to medical specialists.

Regarding the use of potentially inappropriate medication for elderly patients, according to the Beers criteria[9], regardless of the disease and the risk-benefit appraisal of this medication, there were statistically significant differences between service providers, with users of the Brazilian Unified Health System (or SUS) making greater use of NSAIDs, long-duration sulfonylureas and nifedipine, and users of supplementary health plans making greater use of muscular relaxants, estrogen, amiodarone and doxazosin. There are differences in medication use profile depending on whether one has a health plan or not, and the results of the present study confirm similar data from other scientific studies carried out in different regions of Brazil. As a result, the adoption of continuous training policies regarding the pharmacotherapy of elderly patients can avoid harm caused by polymedication, drug interactions, adverse side effects, and the unsuitability of prescriptions for this age group.

The reduction in the number of unsuitable prescriptions and use of medication which is inappropriate for the elderly can occur with both service providers. The availability of new information technologies in the basic health network, as well as the constant updating and pharmacological monitoring of the drugs on the National List of Medications would help professionals of the Brazilian Unified Health System (or SUS) to gain quick access to information about medication. With regard to health plans, investments, both multidisciplinary and within the health team, and investments in shared information systems to provide better care to the elderly would allow a review of the medication prescribed and used.

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Validation of a questionnaire for the evaluation of informal social support for the elderly: section 2.

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Abstract

Objective: The objective of the study was to carry out the factorial validation of the questionnaire for the evaluation of informal social support (ASI) for the elderly. *Method*: It is a descriptive, observational, quantitative type research. It was executed between August and December of 2016 in the municipality of Natal, Rio Grande do Norte and other locations in Brazil. In Inclusion criteria, were have age 60 or older and cognitive ability preserved. We performed Exploratory Factor Analysis (AFE). As criterion of exclusion of the items was adopted a reference value greater than or equal to 0.35 of factorial load and greater or equal to 0.5 of commonality per item. To determine the amount of retained factors, the criteria of own values>1, minimum cumulative explained variance of 60% and parallel Horn analysis were observed. *Results*: A sample of 259 elderly people from the five regions of Brazil was obtained. After AFE, 4 items were excluded due to the poverty of their factorial loads, remaining 20 items in 4 retained factors. *Conclusion*: The instrument has good psychometric properties, such as acceptable factor loads and excellent commonalities.

Keywords: Social Support. Health of the Elderly. Surveys and Questionnaires. Validation Studies. Factor Analysis. Statistics.

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INTRODUCTION

Population aging is a global reality and this demographic and epidemiological change is occurring in Brazil in an accelerated form. By 2050, there will be more than 30 million elderly people in the country[13]. These changes bring new demands for elderly care, based on a broader view of health issues. Understanding care for the elderly considering only aspects related to disease and neglecting important elements, such as social and psychological factors, may hamper integral and effective actions among this population[4,5].

Considering the complexity of the understanding of the health-disease process of the elderly, in 2006 the Brazilian Ministry of Health established the National Policy for the Health of the Elderly Person (or PNSPI) as a priority action for this population, highlighting the active participation of such individuals in society, including continuous participation in social issues and the promotion of socio-educational and health resources aimed at this group[6].

Studies describe how inadequate social conditions are directly associated with indicators of illness or adverse life conditions, and also influence the individual's emotional well-being[7-12]. From this perspective, Social Support (SS), especially informal support, plays an important role as a tool to support the health care of people aged 60 years or older[13,14].

Some authors conceptualize SS as the accessible support for an individual through social ties with other individuals, groups and the community[14]. Squassoni et al.[15] describe social support as a form of information that leads the individual to believe that they are loved, that there are people who care about them, that they are appreciated, valued, and affiliated with groups with mutual responsibilities, and that a differentiation can be made between formal support, formed by a network of professionals and diverse institutions, for example, and informal support[10-16].

Informal Social Support (ISS) refers to any support received from a network of those close to the individual, usually consisting of family members, friends or neighbors, and which can involve diverse aspects such as social interaction, support in day-to-day activities, and material and financial support, among others[8-16]. These aspects can form the latent dimensions of ISS.

The importance of SS is highlighted when informal support networks are considered an essential component for ensuring autonomy, positive self-assessment, greater mental health and life satisfaction[13]. Félix et al.[7], in an integrative literature review, identified a lack of social support as one of the predominant factors for suicide attempts in Brazil, among the overall population, agreeing with findings from another country[16]. For many elderly persons, ISS is the most prominent source of support in their lives.

For the efficient intervention of ISS it is important that the evaluation of this support uses instruments of recognized validity. However, the measurement of this construct has been approached from different perspectives by many researchers, using different assessment tools, and often does not meet minimum validation requirements[17-19]. In addition to this lack of or insufficient use of appropriate instruments, the multidimensionality of the social support construct and the lack of distinction between formal social support (FSS) and ISS have contributed to difficulties in the construction of appropriate instruments, meaning those that are used are excessively generic, making it difficult to compare results between studies, and often leading to imprudent or incomplete evaluations[19].

Regarding the aforementioned validation process, in 2014 the American Educational Research Association (AERA), the American Psychological Association (APA), and the National Council on Measurement in Education (NCME)[19] proposed the development of instruments which included, among other steps, evidence of validity based on content, the response process and internal structure.

One of the ways to statistically examine the internal structure of an instrument is factor analysis[20]. This is a multivariate statistical analysis method that operationalizes abstract concepts, which are difficult to measure, into observable variables, which can be reduced to smaller quantities and a reduced number of factors, facilitating interpretation[21-23]. This technique considers the correlation between the items analyzed, grouping them into factors and limiting the number of uncorrelated variables, increasing the reliability of the instrument[24].

Factor Analysis, especially exploratory analysis, assumes that the evaluated construct is not well defined and is based on the construction of the structure of the instrument analyzed in dimensions, with the creation of a smaller set of variables than the original set[22-25]. In view of the above, the objective of this section is to analyze the factorial validity of the Informal Social Support Questionnaire for the Elderly through Exploratory Factor Analysis (EFA).

METHOD

A descriptive, observational, quantitative type research was performed. The present study was undertaken from January to December 2016, as part of the "Construction and validation of a social support scale for the elderly" project. The present study contemplated the factorial validity stage, based on Exploratory Factor Analysis, focusing on the previous steps in the construction of the instrument, among them, the proposition of items based on a literature review described in a manuscript published by Guedes et al.[17], validity based on content and on the response process, debated in the first section of this collectanea[26].

Data collection took place in person or virtually with a population aged 60 years or older from the city of Natal, in an elderly persons association, a public consultation center and a municipal park, or in other locations in Brazil via e-mail, using the SurveyMonkey® tool. When carried out in person, the participants signed the informed consent form while when contact was virtual, they agreed to participate in the study by clicking on the "I agree" option of the questionnaire.

The inclusion criteria for the study participants were 60 years of age or older, with preserved cognitive levels (no clinical diagnosis of cognitive deficit), capable of answering the questions proposed. Whenever the respondent had no schooling, the presence of a previously trained interviewer was mandatory. For the sample calculation, the total number of respondents followed a minimum proportion of 10 for each variable included in the instrument (24 items), giving a total of 259 individuals, following the criteria described by Hair et al.[22].

Exploratory Factor Analysis was performed using the M PLUS Version 7® statistical program. Variable clustering (type R) and factor extraction were performed with common factor analysis, using Geomin oblique rotation. The tetrachoric/ polychoric matrix was initially run with only one factor and all 24 original items. To interpret the rotated factor matrix, criteria were adopted to evaluate whether the items should be maintained. The initial exclusion criterion of the item was based on guidelines for the identification of significant factor loadings based on sample size, which is 0.35 for populations between 250 and 349 subjects, according to Hair et al.[22]. Items with factor loadings less than 0.35 were excluded. The significance was based on a level of 0.05 and a power of 80%, and standard errors considered twice that of conventional correlation coefficients. Communalities less than 0.50, for the most part, were considered as not being sufficiently explained, and these items were evaluated case by case (after determining the factors). Variables with significant loadings in more than one factor (cross loadings) were evaluated for their inclusion in a given factor, through their intensity of significance and conceptual representation over the given domain (after determining the factors).

The next step was to determine the number of factors. For this, certain criteria were adopted. Only factors with eigenvalues above 1 were extracted. The ideal cumulative Variance considered was equal to or greater than 60% for the number of possible Factors. For the Horn Parallel Analysis criterion for the extraction of Factors, a graphical analysis of the variance curve was performed, establishing the beginning of horizontalization or abrupt drop as a reference point[22].

As the first proposal of reference values for the instrument, values were assigned to the items in proportion to the common variance explained for their factors. "Yes" responses were assigned the maximum values (2 or 4, depending on the item) referring to the item and "no" answers were assigned a score of zero. The reference values of the overall instrument and the dimensions were determined by the median, as the distribution of the sample was not considered normal. The total sample of 259 subjects was considered for the definition of means and medians.

The project was approved by the Ethics Research Committee of the Hospital Universitário Onofre Lopes, under opinion number 1.644.533. The present study complies with Resolutions Nº 196/96 and Nº 466/2012, of the National Health Council (or CNS).

RESULTS

In terms of descriptive analysis, the total sample corresponded to 259 respondents, of whom 73.15% were women and 26.85% were men. Regarding educational level, 34.75% had an elementary level education, 23.17% a secondary level education, and 22.01% a higher level education. A total of 11.58% had no schooling and 8.49% had a postgraduate education. Responses were obtained from the five regions of Brazil, most of which were from the northeast (85.33%) and the southeast (12.36%), followed by other regions (2.32%),.

Regarding the determination of the reference values for the instrument, based on the explained common variance of each factor, 20 possible points were assigned to dimension 1; 14 possible points to dimension 2; 6 possible points to dimension 3; and 10 possible points to dimension 4. The overall mean among the respondents was 40.01 and the overall median was 42; in factor one, 20 points; in factor two, 10 points; in factor three, 6 points; and in factor four, 8 points.

Table 1 shows all the items with their respective factor loadings with one factor extracted. Table 2 shows the common variance explained for the possible factors and their cumulative common variance percentages.

Figure 1 shows the eigenvalue and Horn graph with simulation for the parallel analysis criterion. Table 3 shows the distribution of factor loadings and commonalities with four retained factors. Table 4 shows the items distributed in the four retained factors and the results of medians and means by domains and overall.

Table 1. Factor loadings of the 24 original items of the Informal Social Support Questionnaire for the Elderly, with only one Factor extracted. Natal, Rio Grande do Norte, Brazil, 2018

Items	Factor loadings
1	0.746*
2	0.425*
3	0.576*
4	0.718*
5	0.603*
6	0.587*
7	**0.314****
8	0.480*
9	0.725*
10	0.447*
11	0.661*
12	0.744*
13	0.693*
14	0.591*
15	0.487*
16**	**0.312****
17**	**0.292****
18**	**0.270****

to be continued

Continuation of Table 1

Items	Factor loadings
19	0.620*
20	0.624*
21	0.452*
22	0.628*
23	0.691*
24	0.743*

*Significant for $p<0.05$; **Items and values with factor loadings lower than 0.35.

Table 2. Number of Factors extracted, their own values, percentage explained by the common variance for each possible factor and percentage of the cumulative common variance of the Informal Social Support Questionnaire for the Elderly. Natal, Rio Grande do Norte, Brazil, 2018.

Factor Extracted	Own values	Percentage explained by common variance	Percentage of cumulative common variance
1	7.816	38.7%	38.7%
2	2.374	11.8%	50.5%
3	1.621	8.0%	58.5%
4	**1.368**	**6.8%**	**65.3%**
5	1.121	5.6%	70.9%
6	0.943	4.7%	75.6%
7	0.794	3.9%	79.5%
8	0.777	3.8%	83.3%
9	0.754	3.7%	87.0%
10	0.599	3.0%	90.0%
11	0.563	2.8%	92.8%
12	0.449	2.2%	95.0%
13	0.367	1.8%	96.8%
14	0.341	1.7%	98.5%
15	0.188	0.9%	99.4%
16	0.128	0.6%	100%
17	0.000	0.00%	
18	-0.017		
19	-0.086		
20	-0.100		
Total Own Value	20.203		

Number of factors extracted and percentage of minimum acceptable cumulative common variance and with own values >1 are in bold.

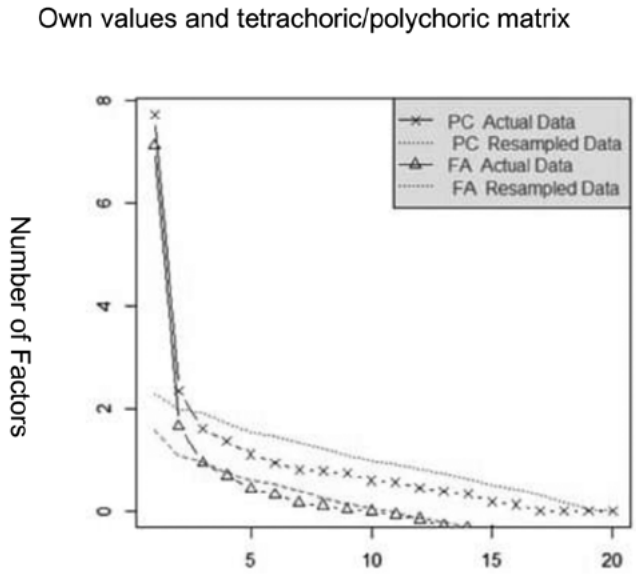

Figure 1. Graph of own values and factor simulation for Horn Parallel Analysis criterion of Informal Social Support Questionnaire for the Elderly. Natal, Rio Grande do Norte, Brazil. 2018.

Table 3. Matrix of rotational factor loadings with four Extracted Factors, 20 items and their respective commonalities of the Informal Social Support Questionnaire for the Elderly. Natal, Rio Grande do Norte, Brazil, 2018.

Factors/Factor loadings of Items	Factor 1	Factor 2	Factor 3	Factor 4	Commonalities
1	0.571**	0.038	0.499*	-0.013	0.842
2	0.041	0.653**	-0.046	0.028	0.903
3	0.650**	-0.054	-0.235	0.239	0.878
4	0.495**	0.239	0.385	-0.065	0.891
5	0.978**	-0.379	-0.012	0.056	0.838
6	0.584**	-0.009	0.041	0.135	0.892
8	0.224	0.351**	0.039	0.093	0.920
9	0.442	0.100	-0.042	0.500**	0.872
10	-0.088	0.886**	-0.196	0.036	0.851
11	0.316	0.547**	0.144	-0.040	0.873
12	0.453*	0.484**	0.167	-0.079	0.881
13	0.386*	0.526**	0.029	0.060	0.903
14	0.035	-0.068	0.817**	0.428	0.851
15	0.111	-0.163	0.265	0.511**	0.902
19	0.044	0.332*	-0.012	0.679**	0.852
20	0.124	-0.018	0.110	0.703**	0.877
21	0.254	0.100	0.353**	-0.005	0.848
22	0.014	0.109	0.585**	0.460*	0.885
23	0.309	0.208	-0.045	0.518**	0.901
24	0.059	0.681**	0.351	0.078	0.862

*Significant for $p<0.05$; ** factor loadings to determine the Factor in which the item was assigned.

Table 4. Final questionnaire with items and factors. Values assigned to items and instrument. Arithmetic means and standard deviation per item. Means by Factor. Overall mean and Median of the instrument, after interviews with the elderly. Natal, Rio Grande do Norte, Brazil, 2018.

Items and Factors	Value attributed to item	Arithmetic Mean Obtained	Standard Deviation
Composition and extension of social network			
1. Can you count on people close to you?	4	3.86	(±0.73)
3. Do you have a friend who you see often?	4	3.32	(±1.50)
4. Do you have anyone in your family you can count on and who lives nearby?	4	3.42	(±1.40)
5. Do you have a friend who lives nearby?	4	3.29	(±1.53)
6. Do you have a neighbor who you can count on when you need them?	4	3.14	(±1.64)
Factor 1 Median	20 points		
Instrumental support and availability			
2. Do you live with a lot of people?	2	0.55	(±0.89)
8. Do you have frequent visitors?	2	1.19	(±0.98)
10. Do you have someone to help with household chores?	2	1.44	(±0.90)
11. Do you have someone to help you leave the house if you need them?	2	1.75	(±0.65)
12. Do you have someone to help you if you are sick or bedridden?	2	1.79	(±0.61)
13. If you are in financial difficulty is there someone who can help you?	2	1.59	(±0.80)
24. Do you have a family member who helps with your care if you need it?	2	1.85	(±0.52)
Factor 2 Median	10 points		
Reciprocity and longitudinality			
14. Do you participate in any family decisions?	2	1.40	(±0.91)
21. Has the help you have had or would have had in the last 30 days been or would have been satisfactory?	2	1.86	(±0.51)
22. Have you received adequate help from others throughout your life?	2	1.59	(±0.80)
Factor 3 Median	6 points		
Emotional support and social participation			
9. Do you have someone to talk to?	2	1.83	(±0.55)
15. Do you participate in decisions among friends?	2	0.89	(±0.99)
19. Do you share leisure time with someone?	2	1.70	(±0.69)
20. Is your social contact with others permanent?	2	1.62	(±0.78)
23. When you are sad or miss someone or something is there someone you can talk to about it?	2	1.54	(±0.84)
Overall Factor 4 Mean	8 points		
Total Mean obtained in interviews	40.01 (±8.20)		
Median (reference value)	42 points		
Total value attributed to instrument	50 points		

DISCUSSION

As the validation of questionnaires is a systematized and continuous process of actions, factorial validation represents an important step in this process[20,21] and is at the center of the discussion of this section of an as yet unfinished collection[17,26]. Factor analysis is an important tool for evaluating the structure of correlations between variables. These variables can be clustered into factors when they are closely correlated, thus forming latent dimensions (identified in this study by type R factorial analysis) that facilitate the understanding of the construct[21,22,24].

Descriptive analysis revealed good variability of the subjects of the sample. There were representatives from elementary and high school, higher and post-graduate educational levels. Elderly persons with an elementary school level of education predominated. Respondents from the five regions of Brazil were obtained, although most were from the northeast of the country. This was partly due to the addition of data from face-to-face interviews that took place in the city of Natal. The predominant gender was female, but there was a considerable absolute sample of men.

Regarding the choice of tools for factorial analysis, rotation of factors allowed the obtaining of a standard that was simpler from an interpretive and theoretically significant perspective. The choice of oblique rotation was due to the need to allow the correlation of the factors related to informal social support, considering the variables chosen[22,24].

Four questions had very poor factor loadings and were eliminated after rotation based on one retained factor. It is possible that misunderstandings in the meaning of these questions by the respondents led to a number of undesirable random responses, interfering with their power to explain the construct and correlation with other variables. Another possibility is that these questions are of debatable relevance to the overall explanation of informal social support, as they may be explained by other questions.

One challenge in research using the factorial analysis method is the choice of the number of factors. A balance is sought between parsimony and the significance of information. Overestimation of the quantity of factors can lead to the production of an exaggerated number of constructs, with a number of excessive and superfluous dimensions with reduced explanatory power. In contrast, a very small number of retained factors could result in a significant loss of information[23,25,27-30].

Analyzing one of the parameters adopted in this research, the "latent root criterion" (eigenvalues>1), Costello and Osborne[28] demonstrated that it tends to overestimate the number of factors retained. In addition, Fava and Velicer[29] demonstrated that such overestimation tends to occur mainly when the factor loadings of the items are low. The factor loadings of the items of this study met the acceptable requirements for the size of the respondent sample. However, the low number of optimal factor loadings (above 0.70) and the presence of factor loadings close to the desired minimum limit[23] were indicative of a small number of factors.

Given the above, we believe that the choice of four factors met a reasonable percentage of the cumulative variance explained and minimized the risk of factor overestimation, achieving a balance between parsimony and significance of information. This choice was also supported by the findings of the Horn Parallel Analysis[25].

Following the choice to exclude four items and the determination of four factors, the matrix was rotated again. All factor loadings were significant and acceptable for the pre-determined parameters. Significant factor loadings demonstrate a correlation between the items and their factors. In addition, the commonalities of the items, when four factors were considered, were excellent (lowest commonality of 0.838). The commonalities represent the amount of variance explained by each variable, demonstrating the close correlation of one variable to the others (shared variance). Crossed factor loadings occurred in small numbers and inclusion in a determined factor was always chosen, based on the level of significance, without the need for conceptual justifications[22,25].

After evaluating the significance of the factor loadings of each item for their proper clustering, the next step was to label the factors, that is, to determine the latent dimensions of each factor. This step is not

determined by the computer program but by the researchers involved. A good theoretical foundation in the understanding of the construct studied and the real aspects that define it is therefore important[23].

In order to choose the labels, items with larger factor loadings were considered to have greater importance in the definition of names, as well as the theoretical-methodological approaches addressed in previous studies. Thus, the dimensions of: *Composition and Extension of Social Network; Instrumental Support and Availability; Reciprocity and Longitudinality; Emotional and Social Participation* were determined.

Some specific dimensions of social support are discussed in literature and support the classifications chosen for the latent dimensions of this study. Studies point to the importance of evaluating social network composition for ISS and highlight some important components, among them, family and friends[16,31]. The importance of evaluating the extension of the social support network for the elderly is also repeatedly mentioned[31].

The category *instrumental support* as an integral part of SS has been the subject of both descriptive research and instrument validation studies[32,33]. Understanding the availability of people close to them, including for day-to-day tasks, can make the elderly feel valued and that they have strong social ties with their support network[16].

Reciprocity can lead to a sense of solidarity[33,34]. Engagement in family decisions, for example, can be a source of this feeling. The theme of longitudinality, however, is still little studied with regard to informal social support. However, aspects of continuity of care have been found to be positive for successful care network models and health outcomes[32]. These factors value the importance of longitudinality as a component for assessing informal social support for the elderly.

Emotional aspects are intimately linked to social interaction and participation and are therefore integral parts of successful ISS and are dimensions constantly referred to in studies on this theme[34,33]. The World Health Organization (WHO) proposes in its International Classification of Functioning[35] the evaluation of social participation for support and relationships.

Regarding the determination of the values for each dimension, factor 1 was the only factor where its items scored the most, with a total of 20 points attributed, that is, 40% of the value of the instrument. This value was very close to the percentage of variance explained for this factor, thus justifying a considerably higher level than the others. The suggested reference values, both overall and by dimensions, represent only an initial proposal. As the sample was not normally distributed, overall and factor medians were used as reference points. Studies with a more refined design, in terms of accuracy, can delimit more precise cutoffs for this instrument, evaluating criteria such as sensitivity and specificity, for example.

Even though most of the items are employed with greater magnitude in the elderly population, the application of this instrument in other populations should not be ruled out, considering its broad approach in dimensions common to several vulnerable groups. This instrument can therefore be an important tool for tracking unsuccessful informal social support, and can be applied in several health services, especially in primary care, seeking to use social networks to support the integral care of people, enhancing the desired results.

Limitations of the study include the fact that, while it included respondents from all regions of the country, the sample was concentrated mostly in the northeast and southeast regions, thus reducing the desirable cultural variability. Part of the respondents answered the questionnaire at distance, which may have favored a greater number of random responses, enhancing the possibility of response bias. A direct evaluation of the cognitive ability of the respondents was not performed, which could increase the risk of elderly people with cognitive deficits answering the questionnaire, impairing the analysis and interpretation of the data.

As informal social support can be considered a multidimensional construct, it is difficult to measure all its aspects and determinants. However, the social support of information is repeatedly highlighted in the literature and was not contemplated in this

instrument. It is prudent to keep in mind the importance of certifying the psychometric qualities of this instrument in other populations and from the perspective of other statistical tools, which can be discussed in later sections.

CONCLUSION

From the evaluation of the results of Exploratory Factor Analysis, the Informal Social Support Questionnaire for the Elderly exhibited good psychometric properties, such as acceptable factor loadings and excellent commonalities. The twenty items that compose the instrument were distributed among four retained factors: *Composition and Extension of the Social Network; Instrumental Support and Availability; Reciprocity and Longitudinality;* and *Emotional Support and Social Participation*.

The suggested reference value for successful informal social support for the elderly was 42 points. Validation studies for the improvement of this questionnaire, in new populations and applying techniques of Confirmatory Factor Analysis and accuracy, are important.

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The contribution of Home Care to the construction of health care networks from the perspective of health professionals and elderly users

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Abstract

Objective: Analyze Home Care (AD) contribution to the consolidation of Health Care Networks(RAS) from the viewpoint of professionals and elderly users. *Method*: Qualitative research, through a semi-structured questionnaire, was carried out.Six professionals were included, by draw, each of them from an occupational category of Home Care Service in Sao Caetano do Sul, São Paulo, Brazil, and also 34 users aged over 60 years-old, conscious and oriented, engaged for, at least one year to AD, carrying HAS and DM simultaneously. *Results*: Subjects' profile - six professionals, five of them with higher education and one with technical education; average age 39, working in Home Care for approximately two years. Users were predominantly women, aged from 60 to 69 years-old, mostly married and with primary education. Data were categorized: Integrality of Health Care; Home Care and access to other health services; Training and skills in Home Care. It was observed integration among professionals of the sector, valuing biopsychosocial context and guiding actions in the care process. However, deficiency in intersectional articulation was detected. *Conclusion*: Co-responsibility, training and professional skills were related to an efficient service. Results showed that a humanized approach, bonding, and the effective participation of caregivers and families favor the execution of a therapeutic project and rehabilitation. Home care interconnects RAS points: de-hospitalization guides health care flow. Nevertheless, RAS members' awareness of Home Care practice, professional training and empowerment of caregivers should be improved.

Keywords: Home Care Services.Integrality in Health. Aging.Longevity. Health Care.

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INTRODUCTION

The Brazilian Unified Health System (*Sistema Único de Saúde* or SUS), created under the 1988 Constitution, establishes Health as a right for everyone and the duty of the State, based on the following doctrine: Universality, Integrality and Equity[1].

In 30 years of the conception and practices of the SUS, there have been challenges and paradoxes between doctrinal idealism and the heterogeneity of practical scenarios, sensitive to epidemiological transitions and to socioeconomic policy. Unprecedented demands require creative approaches and technologies. In this context, the practice of Integrality – the integration of preventive and curative acts, on an individual and collective level, at all levels of healthcare and the valuation of the individual as well as the disease, considering a biopsychosocial approach[2] - is a goal pursued on a daily basis. This semantic plurality makes Integrality a device to organize working relationship, promoting environments of discussion for the review of health processes[3].

In Brazil, increased life expectancy at birth and a reduction in death and birth rates define the process of population aging. This transformation of the age profile has a qualitatively important impact on the morbidity and mortality scenario, revealing a predominance of chronic noncommunicable diseases (CNCD). These require prevention - at different levels - and control through the broad reach, low cost strategies adopted in Primary Health Care (PHC). Inefficiency of actions at this level of complexity leads to an increase in potentially avoidable expenditures.

Based on the epidemiological importance of CNCD in relation to the current health system, there is a fragmentation of care in the Health Care Network (HCN) – the dynamic arrangement of health apparatus, with different levels of technological intensity, which are interconnected, aimed at providing integral care to the user -impairing the effectiveness of primary and secondary prevention actions, culminating in avoidable hospitalizations and high mortality rates due to cardiovascular and cerebrovascular diseases. It is essential to manage care, idealizing interdisciplinary care focused on health promotion and protection, as a priority for rehabilitation[4-6].

In this manner, the Family Health Strategy (FHS) was established in PHC in 1994 to not only contemplate these services, but also to lead the reorganization of PHC, through territorial ascription to interdisciplinary action, active seeking out and the bonding of stable bonds, among other strategies. In the midst of the significant importance of strengthening care at home, Home Care (HC) was subsequently established as a tool to expand practical scenarios and meet user needs.

HC is a federal program that envisages the expansion and qualification of home care under the SUS. Composed of services that are complementary to or substitutes for the hospital and outpatient spheres, it aims at continuity of care and integration into the HCN[7]. It allows full knowledge of the user: their routine, culture and family, and promotes the implementation and articulation of rehabilitation, preventive, educational and health promotion actions[8,9].

Faced with the need to standardize and regulate HC, the Ministry of Health created the Better at Home Program[7] in 2011. In 2013, it increased financial support and technical support to healthcare managers, reformulating regulations and stimulating organized growth[10]. In 2016, it redefined its directives[11,12]. In São Caetano do Sul (São Paulo), this modality emerged in 2012. It includes patients from Home Care II – medium complexity care and Home Care III - high complexity care, with Home Care I patients, who are of low clinical complexity, treated in the FHS[7,13]. The HC morbidity profile is composed mainly of elderly people with CNCD (cardiovascular, cerebrovascular, neoplasia, neurodegenerative conditions), with varying degrees of dependence. Considering the increase in the numbers of cases of these diseases later in life, there is a clear need for specific, qualified care[14].

The transversal nature of HC - communication between segments of different health complexities, valuing co-responsibility independently of hierarchy, adapting real needs to care protocols[15]- ensures efficiency and restructuring of the work process in PHC, especially in hospitals. Consequently, it optimizes

hospitalizations, humanizes care and strengthens institutions, increasing the autonomy of users[16].

The present study sought the following information: how do health professionals from HC -São Caetano do Sul assess the organization of the service in their respective HCN? What strategies are used by the HC professionals to facilitate dialogue between the components of the HCN?

The understanding of HC users regarding the dynamics of care is relevant. A lack of knowledge about levels of complexity and access can generate risks in use and flow. We asked this population: how important is the division of responsibilities between users, family and HC professionals, as well as ease of access and integration with the team, to achieving successful care?

It is hoped that this study will allow the preliminary identification of effective actions, the real needs of users and possibilities for intersectoral dialogue, contributing to the alignment of public policies. The objective is to analyze the contribution of HC to the construction of HCNs, from the perspective of professionals and elderly users.

METHOD

A qualitative study[17] was carried out from November 2016 to January 2017 in São Caetano do Sul, in the state of São Paulo. The subjects of this study were selected from different populations, composing two independent samples: health professionals and users. The data were collected through an interview, of approximately sixty minutes in duration, guided by a semi-structured script[18] containing closed and open questions, with a specific instrument for each sample, proposing a dialogue between researcher and subjects.

The interviews, which were previously scheduled, were carried out by the researcher themselves who, with the express authorization of subjects and managers, then approached the subjects individually and, for the sample of users, authorized relatives and/or caregivers to remain with the patient in cases of physical dependence. The dialogues were recorded, transcribed in their entirety and carried out only once, preserving the spontaneity of the subjects. After transcription the subjects had no further access to the questionnaire. As a basis for the interviews, a questionnaire similar to that of a study developed in Minas Gerais in 2013 was used.[18]

In both questionnaires, data were compiled to characterize the profile of the subjects. The open questions for the health professionals addressed knowledge of organization and articulation within the network; access; communication facilitation strategies among HC actors; professional training. For the users, the aim was to establish notions of access; relationship of responsibility in care between the service, the family and the network user; interdisciplinary action; functioning of HC. In view of the variables presented, categories of discourse analysis were constructed to interpret the results obtained.

The sample universe was the patients and users of the HC network of São Caetano do Sul[19], a choice justified by the high prevalence of elderly users of the public health system, the multiprofessional nature of the network and the previous professional insertion of the researcher in the service and their greater familiarity with the same. This proximity posed a challenge and efforts to preserve impartiality were redoubled. Users were interviewed in their homes; health professionals, at the administrative headquarters of the service.

Of the 16 health professionals of HC-São Caetano do Sul, six subjects were selected, with each category represented at the prerogative of the researcher, in order to value the multiprofessional nature of the service - unitarily in the sample there were: a nurse, a doctor, a nursing assistant, a physiotherapist, a speech therapist and a social worker. For Social Assistance and Speech Therapy, which had a single representative in the sector, inclusion in the sample was automatic; for the other functions, lots were drawn.

Users of both genders were also screened according to the following criteria: age over 60 years, enrollment and minimum follow-up of one year by the HCII or HCIII team; conscious and oriented; patients with systemic arterial hypertension (SAH) and Diabetes *mellitus* (DM), due to the already mentioned epidemiological relevance. The cognitive exclusion criterion was insufficient cognitive capacity

to comprehend the questions. A total of 34 users (28.33%) were selected through analysis of their medical records, out of a total of 120 registered in the HC network. There are approximately 1,000 domiciled SAH and DM (simultaneous) sufferers in the SUS.

In terms of longevity, São Caetano do Sul surpasses the Brazilian average: the life expectancy of 13% of Brazilian elderly persons is 75; for 19.10% of residents of São Caetano do Sul, it is 78[19,20].

The discourses of the subjects were identified with P for professionals and U for users, followed by a specific numeral of each interview.

To comply with ethical principles (Resolution 466/2012 and 510/2016), the present study was assessed by the Director of Basic Health and the Municipal Health Secretary of São Caetano do Sul and approved under opinion number: 1.879.905 by the Ethics Research Committee of the Municipal Health Foundation of São Caetano do Sul. The subjects signed a Free and Informed Consent Form.

RESULTS AND DISCUSSION

All six of the HC professionals were female, and the mean age was 39 years (34 to 50 years). Time spent working in HC (years) and time elapsed since graduation (years) were also evaluated (Figure 1).

Regarding level of education, five professionals (83.33%) had a complete higher education and one participant had a technical qualification. Among the professionals with a higher education interviewed, two had specialization qualifications in HC and/or the FHS: the nurse and the doctor.

There is a high turnover of professionals, whether due to readjustment of hours, non-specific training or administrative issues. Such a panorama necessitates the permanent provision of specialization and improvement courses in HC[18,21,22].

In the sample of 34 users, the female gender predominated. Figure 2 shows the age group of the users.

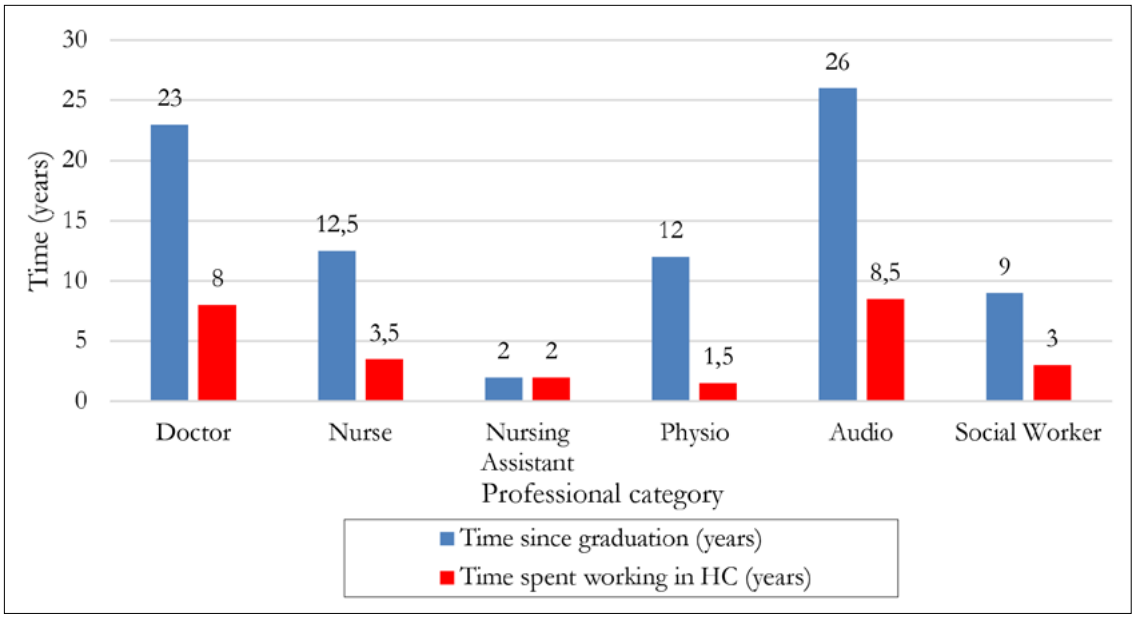

Figure 1. Time spent working (years) in HC service and time since graduating (years) of HC professionals. São Caetano do Sul, São Paulo, Brazil, 2017.

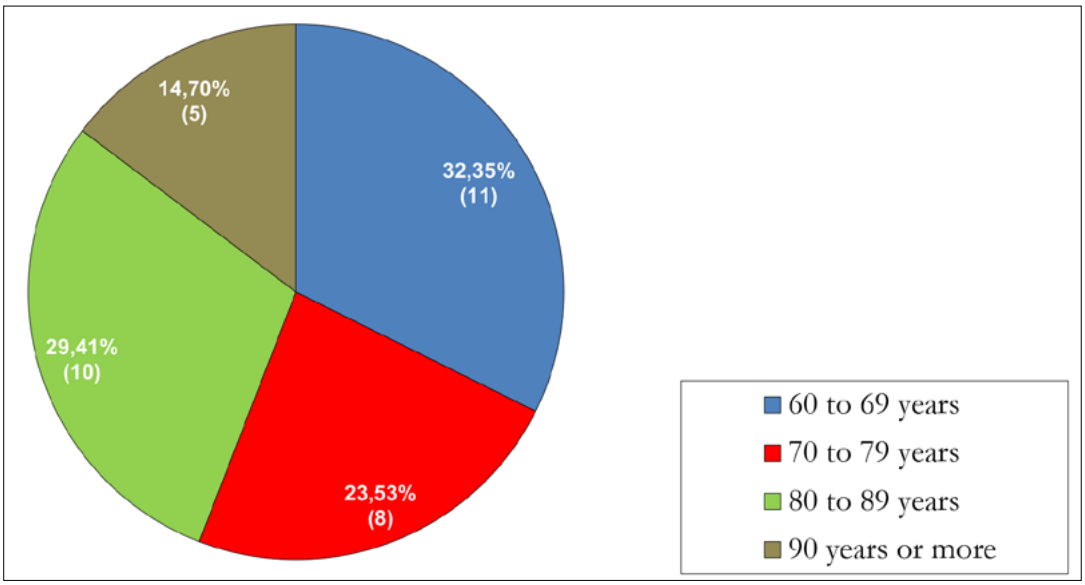

Figure 2. Age distribution of sample of HC users (N=34). São Caetano do Sul, São Paulo, Brazil, 2017.

Regarding marital status, four categories were cited: married (44.12%) (n=15) of the total; widowed (41.18%) (n=14); single (11.76%) (n=4); and separated (2.94%) (n=1). Educational level was distributed as follows: 82% (n=3) were illiterate, 61.77% (n=21) had completed primary education, 23.53% (n=8) had completed high school and 5.88% (n=2) had a higher level education.

Of the users, 85.29% (n=29) received medium complexity care and 14.71% (n=5) high complexity, according to the Katz scale[23,24], which defines categories of dependence according to performance in the basic activities of daily living (bathing, clothing, personal hygiene, transference, continence and feeding). Figure 3 illustrates this distribution.

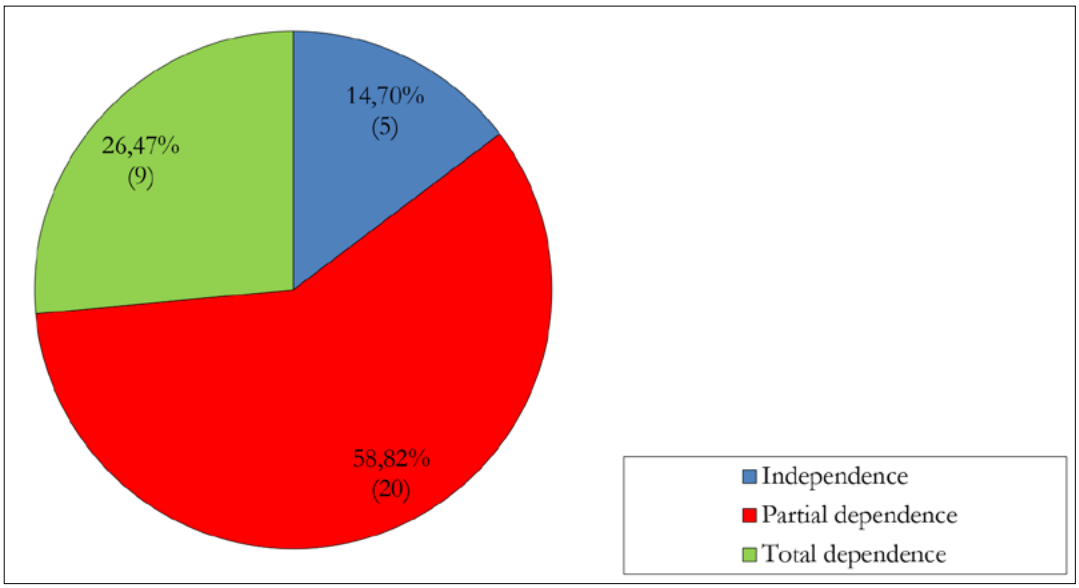

Figure 3. Degree of dependence of HC users (N=34) according to Katz[23]. São Caetano do Sul, São Paulo, Brazil, 2017.

Most of the elderly persons had good ties with health professionals, their family and caregivers. They considered the public sector responsible for difficulties in attending to their needs (access, Integrality, Equity) and in assistance with the management of their physical and cognitive disabilities, sometimes contributing little to satisfactory performance in their activities of daily living[25,26].

As identified by Veras[27], increased longevity leads to greater use of public and private health services, generating more costs and threatening the sustainability of the system. One way of preventing collapse is to invest in policies for disease prevention, stabilization of chronic diseases and maintenance of the functional capacity of the sick.

Regarding socioeconomic profile, there is a heterogeneity in the conditions and location of housing and resources available to families. Extremes were identified, from the 24-hour permanence of caregivers to users who were alone and did not have such support. The caregiver emerges as a fundamental actor for users with partial or total dependence in the performance of daily life activities (Figure 4).

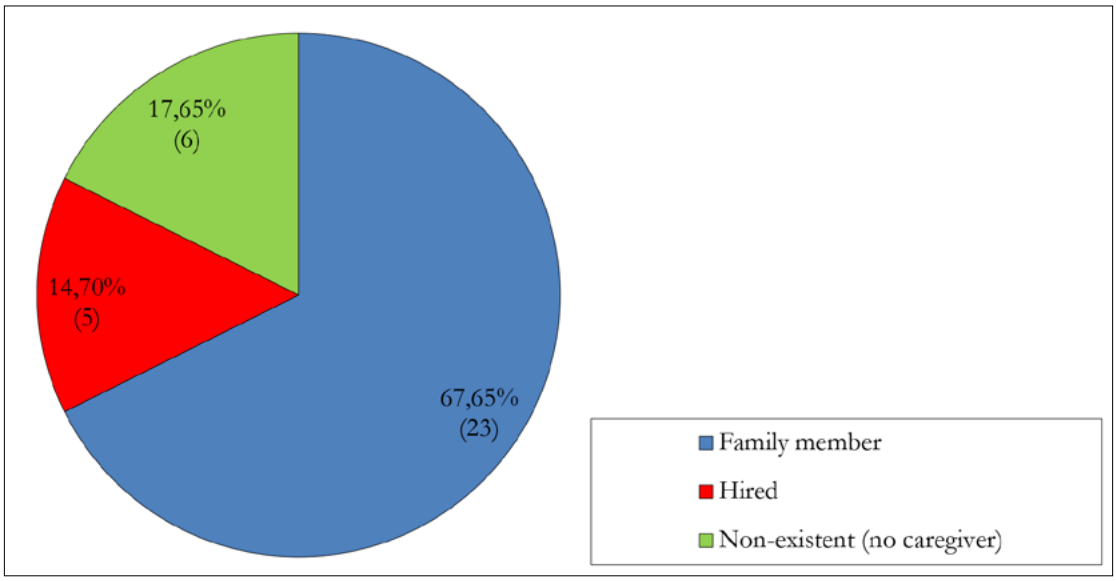

Figure 4. Distribution of sample of HC patients from São Caetano do Sul, (N=34), based on existence of caregiver and nature of caregiver-patient relationship. São Caetano do Sul, São Paulo, Brazil, 2017.

In order to systematize the information, the analysis of the data obtained consisted of three categories of analysis: Integrality of health care; HC and access to other health services; Interdisciplinary team, training and skills in HC.

Integrality of health care

Professionals and users cite important characteristics for the effective construction of the health care network, such as continuous and comprehensive provision of care:

"When I was discharged, I was promptly attended to at my home by a team with several professionals, who provided all the necessary care ... However, on another visit I noticed that one professional did not give the same instructions as the other and I got confused in following them [...]"(U8).

"[...] We try to plan the first home visit in a team so that we can establish a single line of care [...]"(P6).

"[...] The HC network can link up with other services, but many professionals are constantly changing, and teams that aren't big enough feel the effects [...]" (P3).

The incongruence of the team is observed in decision-making, making patient adherence and the measuring of results difficult. Adding to this scenario, the lack of counter-referral makes the network disconnected. Perhaps this is why HC was mentioned as a specific form of care to be used at a certain time, and is not seen as integral care[14,28,29].

> "[...] When I refer my patient to the specialist, I am careful to send a letter explaining the case. However, when the case returns, I receive no guidance or explanation as to the proposed conduct [...]"(P2).

The existence of an integrated computerized system for recording information could facilitate communication between the various points of the network.

> "[...] when I need treatment in another of the city's services, I have to tell my whole story again. There is no conversation among professionals, not even with an information system [...]"(U14).

The subjects demonstrated an understanding of the organization of health services linked to the provision of care, generally related to different degrees of complexity established by the organization of SUS: PHC, represented by the Basic Health Units (UBS) or Family Health teams; Secondary Care, represented by specialist centers; Tertiary Care, represented by the hospital network. In São Caetano do Sul, the hospital network is considered to be secondary level of complexity.

> "[...] There are health centers, which we almost always use ... There is the municipal hospital, emergency units and there are also the specialist centers [...]" (U12).

When HCII and HCIII were specifically addressed, the subjects understood these to be care modalities within the HCN. However, they referred to the absence of flows and protocols to guide and optimize the services of the network.

> "[...] I'd emphasize the need to create protocols and improve the registration of information in medical records to improve the work process and avoid the loss of the patient's history [...]" (P4).

> "[...] I see a difference in the care provided by the professionals... I'm treated one way in HC, and other way at the BHU, and another way at the hospital [...]" (U13).

While there is a longitudinal approach, that is, ongoing care based on the protocols of the teams, interdisciplinarity - desirable for the improvement of care - still requires adjustment, with the autonomous actions of each specialty prevailing, reflecting only the multidisciplinary nature of care.

Dehospitalization triggers the flow of care offered by HCNs, with HC of strategic importance. Interdisciplinary dialogue, intra-hospital visits, and the planning and training of the care to be offered at home are essential measures of articulation within the system, adding an integrative vision to the health-disease process. In the interviews with the professionals, there were references to problems to be overcome, such as: the difficulties of families in providing care, the acquisition of equipment, the adapting of homes, the difficulty in finding home care professionals, the fragmentation of care and the lack of health education provided at discharge.

> "[...] The social worker and the nurse paid a visit to the hospital before discharge. There they informed us about how it would work at home and what the HCN follow-up would be like [...]" (U7).

> "[...] I started my examination of the patient's history in the hospital, when we are called by them to start the de-hospitalization process [...]" (P6).

It was identified that HC has a mediating role between patient, caregiver, professionals and the health system, especially in the process of dehospitalization, offering positive results in the hospital-home transition, an impression corroborated by the users. The exchange of knowledge and experiences between these actors minimizes the fragmentation of care and contemplates several dimensions of care. Nevertheless, the experience described by the social care and nursing professionals allows them to understand the importance of home care to integrality and continued care.

An important initiative cited by interviewees was the use of matrixing moments[30] with the Family Health teams to discuss the cases to be referred to HCII and HCIII.

> "[...] I take part in the matrix planning meetings of the family health teams every week. It is an enriching moment, since it allows dialogue about referral and counter-referral between the FHS and HC, as well as the chance to discuss the profile of the patients and referrals [...]" (P4).

In this way, the contribution of the HC to the networks can be inferred, with strengthening necessary through interdisciplinary meetings for the implantation of flows and protocols and the improvement of the provision of services.

Home care and access to other health services

Analyzing the behavior of the actors in the care process helps to improve the system, as it allows discussion of the ways to overcome gaps in the implementation of Home Care in the HCNs, in the pursuit of Integrality[2,3,31].

> "[...] when we are sent to the service in another part of the network, we wait the same time as the other patients, but we are bedridden and we should have priority ... We wait when the appointment is scheduled and we wait to schedule it ... We get a different level of service when the health professionals intervene" (U8).

> "[...] Often the process does not work and we use personal contact to solve the problems of the users. This communication needs to be improved. [...]" (P4).

> "[...] The Interdisciplinary Team needs to prioritize and establish a schedule of visits and procedures [...]" (U9).

> "[...] the HC works only during the week and during business hours, this means that we use the emergency room frequently at weekends and at night, even just to use medications [...]" (U5).

> "[...] there is a need for dialogue among HC professionals so that we can share and plan the treatment of the patient together [...]" (P5).

The analysis of the interviews reveals difficulties regarding access, explained in intercurrences outside the hours of operation of the service and the absence of priority treatment, in addition to problems originating in the alignment of conduct among the team.

Given these limitations, it is emphasized that the care given to the user is not always focused on a holistic approach and sharing responsibilities with the family, which would optimize home-based alternatives.

The users use different services in several points of the HCN, as they have unstable clinical conditions, which generates insecurity among their family and caregivers, despite the guidelines received. It is necessary to expand and align the services offered by the HCN[32].

It is vital to establish a relationship between the services, as the clinical picture tends to be heterogeneous, overlapping and endowed with multiple intervening factors. HC is capable of transmitting security to family and patients since, as besides the technical specificity of the care it provides, it promotes access to other apparatus (referral) according to the qualification of need (Principle of Equity).

Interdisciplinary team, training and skills in home care

The professional training refers to the idea of adding to and updating knowledge or skills, essential strategies for health care.

> "[...] There is a need to standardize HC care so that all the professionals use the same language and approach [...]" (P6).

High turnover and the inadequate composition of the interdisciplinary team suggests weaknesses in the work process, culminating with the impression of unqualified care.

> "[...] I see a need to provide a greater number of professionals to offer full care, as well as offering a complete interdisciplinary team to carry out the service [...]" (P2).

HC practices do not replace the process of technical training. There are professionals who have worked for a long time in the service, however, without specific HC or FHS qualifications, resulting in a perspective that is sometimes merely centered on the individual and their treatment, excluding health promotion strategies. Interdisciplinary meetings can result in considerable gains in the structuring of HC.

> "[...] the lack of team meetings means the improvement of actions and procedures in HC is impossible [...]" (P4).

The interdisciplinary team presents difficulties in the construction of dialogue with the services provided, in spite of the existence of clinical criteria that delimit fields of action and referral requirements. A bureaucratic, non-resolutive approach prevails, imposing barriers for users. Strategies that optimize supply in relation to demand should be adopted[33].

Linking and reception are employed in the search for effective customer service from the first intervention until discharge. Integrating Home Care into the HCN is a great challenge, notably for Family Health teams[33].

> "There is a great dependence of users on the care offered to the patient or family member ... Even after guidance from the team regarding basic care ... the family is reluctant to carry it out [...]" (P6).

> "[...] I feel secure when the HC team takes over care [...]" (U17).

The emphasis on care dimensions involving all actors, such as the family approach, training caregivers and providing guidance on the services offered in the various points of the HCN, encourages the promotion of qualitative changes and reinforces commitment among health professionals, individuals, families and the community.

Considering these strategies, the professionals cite tools that they consider essential to adapt Home Care to the HCN: implantation of electronic records, the definition of protocols, the emphasizing of the adequacy of instruments that facilitate the practice of care; the withholding of the hospital bed for the continuity of treatment.

The importance of constant training for professionals and caregivers was also cited. The matrix support strategy is a rich space for sharing knowledge, interdisciplinarity and the construction of therapeutic planning directed at individuality. It is up to the professionals to guarantee the integrality of the practices adopted[34].

Thus, Home Care forms part of the HCN as a device for the restructuring of service, a facilitator of dialogue through the actions of dehospitalization, matrix planning and the domiciliary visits of the interdisciplinary team, contributing to a reduction in costs, by reducing the time and number of hospitalizations and minimizing the demand for emergency care services[7,18,35].

As it is a modality of care within Brazil, there are difficulties regarding the consolidation of Home Care in parallel with the HCN: a lack of clarity on the part of users regarding the operation of the service, the reduced supply of equipment and infrastructure and insufficient investment in specific training for professionals. The expansion of the HCN brings the possibility of strengthening HC, making it the communication hub between services.

Although the statements of the interviewees allow some favorable inferences regarding the role of HC in the categories considered, as well as the construction of hypotheses that will be subsequently tested, it would be premature to be satisfied with the assertiveness of the answers to the questions that guide the present study, due to the plurality and subjectivity of the content obtained. The design, by itself, presupposes a systematized complement so that the information and evidence collected here supports the strengthening of HCNs. Over time, integrating categories through responses is a valuable exercise in understanding the interdependence of processes and selecting priorities.

CONCLUSION

In the midst of the existence of correlated care modalities that contemplate different levels of complexity in the Brazilian health system, Home Care occupies a well-defined niche:

interdisciplinary therapeutic planning, with practices that favor alignment among all the actors involved (professional, family, caregiver, patient) carried out at home, with constant management and reassessment of the actions in the Health Care Networks. This construction process, when developed in an integrated and phased manner, favors quick decision making and offers a satisfactory safety margin, prerequisites for effectiveness with patients of medium and high complexity.

Communication and articulation between points of the Health Care Network are foundations for a transversal approach. Examples include: deployment of recovery beds, systematization of the work process to encourage counter-referrals; interface with Basic Care to improvement patient care, avoiding unnecessary hospitalizations; flexibility in hours of Home Care functioning.

Hospital discharge implies optimizing services and avoiding rehospitalization. Home Care seems to respond to the interlocution and execution of the process, with respect to the readjustment and even the transfer of care to the home context in order to guarantee the continuity of the service which began in the hospital network.

The importance of a collective approach is clear, from tripartite development to the formulation, revision and execution of protocols that favor interprofessional communication in the various sectors of care, establishing information flow and embracing the concept of Integrality, reducing iatrogenesis. Qualified listening with an interdisciplinary team duly prepared to approach and address needs inherent to senescence and the peculiarities of the home, will allow the construction of a feasible and shared therapeutic plan.

Further studies are also needed to detect and explore the potentialities and weaknesses of Home Care so that there is sufficient support for robust conclusions and the possibility of expanding the strategies offered to different biopsychosocial contexts and Health Care Network structures.

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Factors influencing the condition of vulnerability among the elderly

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Abstract

Objective: Describe health conditions and life habits using Vulnerable Elders Survey-13 scores, with the aim of understanding the factors associated with the vulnerability of the elderly. *Method*: A quantitative, cross-sectional study was conducted in the Distrito Federal, Brazil. Data were collected by a questionnaire containing the Vulnerable Elders Survey-13 and other variables. Descriptive statistics, correlation and regression analyses were carried out. *Results*: 956 people aged 60 years and older living in the Distrito Federal were interviewed. Of these, 32.4% had scores equal to or greater than three, and were therefore classified as vulnerable. Some variables exhibited a positive relation with VES-13 score, with intensity ranging from very weak, in the case of systemic arterial hypertension (p=0.035) and *diabetes mellitus* (p=0.027), to moderate, as was the case with depression (p<0.001), urinary loss (p<0.001) and falls (p<0.001). It was also observed that a 1% increase in the income of the elderly resulted in a reduction of 0.27 points (p<0,001) in Vulnerable Elders Survey score, reducing vulnerability. *Conclusion*: Depression most influenced vulnerability score, followed by urinary and hearing loss. Public policies aimed at the promotion of the physical and mental health of the elderly and the creation of a propitious environment to increase income, through reinsertion into the labor market or welfare policies, can help to reduce vulnerability.

Keywords: Health of the Elderly. Risk Factors. Health Vulnerability.

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INTRODUCTION

Although the terms "frailty" and "vulnerability" are widely used in gerontological literature, they are not the same. In the present study, the term vulnerability shall be taken as referring to an increased risk of functional decline or death[1] over a period of two years, in relation to biological and physiological factors.

Measures to appraise vulnerability are important for identifying elderly people at an increased risk of deterioration of health, who are an important target for interdisciplinary intervention. Identifying people aged 60 or over who are in a situation of vulnerability, with risk of functional decline and incapacity a large and significant step towards the construction and prioritization of adequate care for these patients[2,3].

Studies exist in literature that describe screening instruments for functional decline and the quality of life of elderly people[4,5]. One of these is the *Vulnerable Elders Survey-13* (VES-13)[1], an instrument which predicts the occurrence of the functional disability, death, and institutionalization of the elderly person[6]. The appraisal of vulnerability is extremely important, and this test has even been included in the Health Guidebook for the Elderly Person 2014 of the Brazilian Ministry of Health, where it was entitled the Protocol for Identification of the Vulnerable Elderly Person – VES-13. It is a key feature of this Health Guidebook[7].

The identification of health and living conditions related to the loss of functionality in the elderly person, represents an important contribution to the planning of public policies and interventions, which help people aged 60 or over live with more independence and less functional loss[3]. The health professional responsible for caring for the elderly person, when making an early identification of the factors that lead to functional disability, can also instigate interventions that would otherwise likely not have been considered.

The aim of the present study is to establish a link between the VES-13 score and health conditions and living habits, seeking to understand what factors are linked to the vulnerability of the elderly person.

METHOD

Through a quantitative and transversal study, we evaluated primary data related to the health and living conditions of elderly people resident in the Distrito Federal, Brazil. This study arose out of a survey carried out in the Distrito Federal between 2012 and 2015, entitled "The Health Situation, Life and Death of the elderly population living in the Distrito Federal"[8].

The survey was carried out at the 15 regional health offices of the Distrito Federal, during the campaign for vaccination against influenza, carried out in 2014, with the vaccination of 90.7% of the elderly population of the region.

The sample was stratified and is representative for each regional health office. Sample size calculation identified a need to interview 935 elderly persons in the DF.

The sample calculations were performed in two stages, the first stage calculated the sample of vaccination points and the second stage calculated the sample of the elderly population.

Stage 1: A stratified sample was taken of all the vaccination points, in proportion to the number of elderly people by region. The calculation base used was the set of fixed vaccination points in 2012 (146 in all). In order to obtain representative results for each health region, the study was carried out at one vaccination post for each Regional Health Office (RHO), with two vaccination points surveyed in the Ceilândia RHO, three in the Taguatinga RHO, and four in the Southern and Northern RHOs, resulting in a total of 20 vaccination points.

The vaccination points surveyed for each RHO were chosen at random.

Stage 2: To calculate a representative sample of elderly people who were to take part in the survey, the following formula was used:

$$n = \frac{n_0}{1 + \frac{n_0}{N}} \qquad n_0 = \frac{p(1-p)}{D^2},$$

where "p" and "D" are coefficients of proportion and error related to the target public, and N is the total size of the subpopulation. Each RHO was considered as a subpopulation of the elderly population of the Distrito Federal.

For the sample calculation, population data based on the 2010 census of the Brazilian Institute for Geography and Statistics (or IBGE) was used[9].

To select the elderly people who took part in the interviews, we used the systematic sampling technique, as follows the second of every two elderly people who provided their vaccination card at the vaccination point was invited to participate in the study. This person was given a Free and Informed Consent Form, approved by the research and ethics committee, which was read to with the interviewee, who was able to ask questions. If the individual agreed to take part in the study, the form was then duly signed.

The criteria for inclusion in the sample were: people aged 60 or over who lived in the Distrito Federal, In cases where the elderly person was unable to participate in the interview, then their companion should know the elderly person well enough to answer the questions of the questionnaire. Elderly people who were bedridden or those who did not arrive at the vaccination points were excluded from the study.

A total of 30 interviewers were selected, all of whom were people who worked with the elderly or had some proximity to the issue of ageing. These interviewers received 12 hours of training, divided into three sessions. The first session was become familiar with the questionnaire, standardize the questions and apply the questionnaire within the group; the second meeting was to apply the questionnaire among elderly people in the community; and the third was to resolve any concerns and make adjustments to the questionnaire, before drafting the final version.

The instrument for data collection was a questionnaire of closed questions, containing VES-13 and also other questions about health and living conditions. The first version of the questionnaire was constructed by taking other questionnaires into account. This version was sent to four experts in ageing, and any readaptations were made.

On data collection days, the elderly people were approached while in the vaccination queue, and then invited to answer the questions of the interviewer in a more reserved space, close to the vaccination point.

The questionnaire as applied contained the following:

Vulnerable Elders Survey-13 (VES-13): This is a simple tool, available in the public domain, which identifies vulnerable elderly people living in the community. The authors of this instrument define a vulnerable elderly person as someone aged 65 or over, who has an increased risk of functional decline or death over the next two years[1]. This tool was developed and validated in the USA[1] and a version culturally adapted for Brazil was released in 2012, in which an elderly person is considered as being 60 years old or over, in compliance with the terms of Brazilian legislation[2]. The Brazilian Ministry for Health used this instrument within the Health Guidebook for the Elderly Person, 2014, where it was given the name of Protocol for Identification of the Vulnerable Elderly Person VES -13[7].

The VES-13 gives points for aspects such as age, self-perception of health, physical limitations, and functional disabilities, generating a point score varying from 0 to 10, with 0 representing the lowest degree of vulnerability and 10 the highest. The identification of an elderly person as vulnerable (with a point score of 3 or more) shows that vulnerable elderly people thus identified are 4.2 times more likely to experience functional decline or death over a period of two years[1]. In contrast, a score of less than three represents the absence of conditions of vulnerability. An analysis of 420 elderly people revealed that the risk of death or functional decline increases by 23% with a VES-13 score of three, and 60% with a VES-13 score of ten[10]. Awareness of the VES-13 score of the population therefore provides knowledge of the level of vulnerability. This instrument has a sensitivity of 82% and a specificity of 79%, when used for elderly people without cancer[11].

The other variables considered were: income, Body Mass Index (BMI), quantity of medication used daily, regular physical exercise, cigarette smoking, calf circumference, a fall in the last 12 months, urinary

incontinence, hearing and sight problems which affect daily activities, and self-reports of medical diagnoses of high blood pressure, diabetes, arthritis, depression, and osteoporosis.

The study set out to discover whether there is any link between VES-13 test score and the variables as previously mentioned.

Excel 2013 was used for descriptive analysis. To identify the factors that could influence the vulnerability of elderly people, two separate approaches were used. The first seeks to identify the relationships of dependence that may exist between the selected variables and the VES-13 score. This analysis tries to identify whether any of the factors listed above is related to this score in some way. For the variables measured on a numeric scale, such as calf circumference, BMI and income, correlation analysis was used to identify if there was a relationship. For others, where the answers were given as contextual answers such as "has" or "doesn't have", the chi-squared test was used to see if a relationship existed. We also used Cramér's V test to check the intensity of the relationship, which could be considered very weak, weak, moderate, strong and very strong. The SPSS 22.0 *software* program was used to classify the same.

The second analysis was based on the estimation of a statistical model that seeks to capture, at specific points, the existing relationship between each variable and VES-13 score. For this, the following model was used:

$$VES13 = \beta_1 LnIncome + \beta_2 LnBMI + \beta_3 LnCalf + \beta_4 Hypert. + \beta_5 Diab. + \beta_6 Depr. + \beta_7 Sight + \beta_8 Osteop. + \beta_9 Urine + \beta_{10} Med. + \beta_{11} Hearing + \beta_{12} Fall + \varepsilon$$

Where:

LnIncome= Natural logarithm of income as informed by the interviewee;

LnBMI= Natural logarithm of Body Mass Index, calculated based on the height and weight of the person interviewed;

LnCalf.= Natural logarithm of the interviewee's calf circumference, as measured at the time of application of the questionnaire;

Hypert.= Hypertension;

Diab.= *Diabetes Mellitus*;

Depr.= Depression;

Sight= Vision problems that hinder daily activities;

Osteop.= Osteoporosis

Urine = Frequent urinary incontinence

Med.= Number of types of medication that the interviewee takes daily.

Hearing.= Hearing problems that hinder daily activities.

Fall= Indicates whether the interviewee has had a fall over the last 12 months;

Finally, ε is the estimation residue.

In a first analysis of the model, the presence of heteroscedasticity was noted. The robust model was therefore estimated, applying the correction as proposed by White, which corrects the possible bias of a previous model. In the case of income, BMI and calf circumference, which have different dimensions, the natural logarithm was applied to remove the bias in the result, and also to allow analysis in percentage terms, which means that the coefficient presented in Table 2 is the result of a 1% variation in these variables.

This research study was duly approved by the Research and Ethics Committee (REC) of the Foundation for Teaching and Research in the Life Sciences (*or* FEPECS), under Opinion Statement No. 143,846, on 12 November 2012, according to National Health Council Resolution No. 466 of 2012.

RESULTS

In this study, 956 people aged 60 or over, resident in the Distrito Federal (DF) were interviewed. Of this sample, 438 (45.8%) were between 60 and 69 years old; 386 (40.4%) were in their seventies, 1331 (13.7%) were in their 80 and 99 years old and only one person was a hundred or older. In addition, 581 (60.8%) of the elderly people were female and 373 (39.0%) were male: two declined to answer.

Of those interviewed in this study, 456 (47.7%) considered their health to be fair or poor.

It was observed that 639 (66.8%) of the elderly people had a VES-13 score between zero and two points, and 310 (32.4%) had a score of three points or more. Table 1 describes the scores of the Protocol for the Identification of the Vulnerable Elderly Person, as recorded by the interviewees.

Table 1. Scores of the Protocol for the Identification of the Vulnerable Elderly Person (N=956), Brasília, DF, Brazil, 2014.

Scores	n (%)
0	281 (29.4)
1	242 (25.3)
2	116 (12.1)
3	117 (12.2)
4	35 (3.7)
5	28 (2.9)
6	39 (4.1)
7	58 (6.1)
8	22 (2.3)
9	5 (0.5)
10	6 (0.6)
Did not answer	7 (0.7)

Individuals who did not answer enough questions to obtain a VES-13 score were excluded. The presence or absence of a relationship between the variables was assessed by analysis of data cross-referencing and the application of the chi-squared test.

Positive relationships were found between the variables, albeit with differing intensities. In the case of hypertension (p=0.035) and diabetes (p=0.027), the dependence between the variables was shown to be very weak, with Cramer's V varying between 0 and 0.15. In the cases of presence of arthritis (p<0.01) and osteoporosis (p<0.01) the relationship was weak, with a Cramer's V of between 0.15 and 0.20. Variables with a moderate relationship, with Cramer's V ranging from 0.20 to 0.25, were: depression (p<0.01), sight problems (p<0.01), urinary incontinence (p<0.01), hearing problems (p<0.01), regular physical exercise (p<0.01) and occurrence of falls.

The relationship between smoking and VES-13 score was not statistically relevant, with p=0.96. In the case of numeric variables, correlation analysis identified an inverse yet weak relationship between income and VES-13 score (p<0.01). Body mass index also revealed a weak and directly proportional correlation (p=0.06), while there was a weak and inversely proportional relationship with calf circumference (p=0.05). The number of medications applied revealed a weak positive correlation (p<0.01).

Multivariate analysis identifies how much each variable contributes towards the vulnerability score, and depression was found to have the greatest influence, contributing 0.94 points, or almost one whole point, to VES-13 score (p<0.01). Urinary loss adds an additional 0.73 points to the VES-13 score (p<0.01). Each additional type of medication applied resulted in an increase of approximately 0.089 points to the VES-13 score (p<0.01).

A summary of these results is shown in Table 2. The variables are shown in order of decreasing impact on VES-13 score.

Table 2. Coefficients of multivariate analysis, Brasília, DF, Brazil, 2019.

Variables	Coefficient	Standard Error	*p*-value
Depression	0.946	0.297	0.002
Body Mass Index *,	0.830	0.742	0.263
Urinary incontinence	0.730	0.211	0.001
Hearing problems	0.670	0.231	0.004
Osteoporosis	0.658	0.224	0.003
Sight problems	0.616	0.209	0.003
Falls	0.381	0.198	0.055
Income*	-0.278	0.073	0.000
Diabetes	0.233	0.198	0.239
Number of Medications	0.089	0.030	0.004
Hypertension	-0.055	0.200	0.783
Calf circumference *	0.050	0.683	0.942

$R^2 = 0.5563$; F-test < 0.001; *Estimated variables shown as Natural logarithms;

As the p-value was over 0.1, the impact of calf circumference, hypertension, diabetes, and BMI could not be confirmed through multivariate analysis.

The estimated model obtained an R^2 value of 0.55, which suggests that the model used can explain over 55% of variations to VES-13, with the other 45% being explained by other variables not included in the model. As the model explains over 50%, this can be considered satisfactory. Furthermore, the F-test score was less than 0.01, which shows that the variables used, when taken jointly, are sufficient to explain the variations in the VES-13 scores.

An increase of 1% in the income of the elderly person was found to cause a reduction of 0.27 points in VES-13 score *(p<0.01)*.

DISCUSSION

Of the elderly people interviewed, 32.4% were considered vulnerable, a proportion close to that found in the first study conducted on VES-13, in which 32.3% of the elderly people were found to have a score of three points or more.

Another study carried out with people aged 70 or over found that 38.0% of the sample had a point score ≥3. Contrary to the findings of the first study, this study reached the conclusion that VES-13 shows a somewhat limited predictive precision when predicting mortality and admission to emergency units[12].

Depression known to be a factor that reduces functional capacity, but in this study the presence of the same increased VES-13 score by almost a whole point. Among elderly patients with heart problems, depression has been found to be very common, with a major impact upon independence and also upon the quality of life of these people[13]. Another study carried out in Lafaiete Coutinho, in the Brazilian state of Bahia, showed that elderly people with prior symptoms of depression ran a greater risk of becoming dependent on others, even for the most basic activities of daily living, regardless of their gender, age bracket, per-head family income, presence of diabetes, use of medication, or level of physical activities[3].

A study carried out on housebound patients showed that the presence of urinary incontinence also raised the mortality rate, which was 24.9% over a two and a half year period, compared to a rate of 12.8% mortality in the group without urinary incontinence[14]. Another study, this one in 2018, found data that confirmed that elderly people with urinary incontinence had a greater likelihood of functional disability for activities of daily living[15].

Income is a mechanism for social protection, and an increase in salary is linked to a reduction in VES-13 points, and hence to a reduction in the risk of disability or death. In 2003, 10.8% of elderly people had no income, representing a total of 1.5 million individuals, of whom 80% were women, generally of more advanced age, economically disadvantaged, and with a reduced role in the employment market, as well as reporting worse conditions of health and lower functional autonomy[16].

In 2014, the income of elderly people was made up of retirement pay (53.4%), income from work (40.8%), pensions and other sources, including the state pension. Since the 1990s, there has been a fall in the proportional participation of elderly people in the workforce, with the work activities of elderly people declining by 12%. This was because in 2013 the average age of retirement among Brazilians was 54 years old, affecting the decision to retire while still able to work. The fact that the elderly retiree experiences unstable employment conditions upon returning to work also has an influence on his or her return to the employment market[17].

The main bias contained in this study is the fact that it does not include housebound elderly people, as these have the option of being vaccinated at home. This means that some of the more dependent elderly people would not attend the vaccination points, and hence would have no possibility of being interviewed. The prior training of the evaluators for the application of the interviews and of the physical performance tests largely rules out the possibility of evaluation bias. However, there is the possibility that the results of self-reported measurements may be influenced by cultural and social factors.

CONCLUSION

The results of this study show that a significant part of the elderly population demonstrate a risk of vulnerability, especially with the effects of variables such as depression, urinary incontinence, hearing difficulties, osteoporosis, visual difficulties, falls, number of medications in use, and family income, which interfere with the vulnerability score of the elderly person.

A rise in income, even if small (1.0%), reduces the *Vulnerable Elders Survey-13* score and, hence, the elderly person's degree of vulnerability.

The identification of the vulnerability of elderly people prior to significant functional decline facilitates the establishing a course of action that provides greater independence and quality of life for these individuals, as illnesses and health disorders can harm functional systems through a range of mechanisms, and can even lead to disability and/or death.

Efficient government policies aimed at the promotion of physical and mental health for the well-being of the elderly population, and the creation of an environment that helps to boost income through reinsertion in the employment market or through welfare policies, can help to reduce vulnerability.

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Evaluation of functional disability and associated factors in the elderly

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Abstract

Objective: To estimate the prevalence and self-reported socio-demographic and health factors associated with functional disability in basic and instrumental activities of daily living among the elderly. *Method*: A cross-sectional study was carried out, based on a representative sample of elderly people receiving care at a reference unit in the north of the state of Minas Gerais. The data were collected in 2015. Demographic and socioeconomic variables, morbidity, hospitalizations in the previous year, frailty (Edmonton Frail Scale), geriatric depression (GDS-15), and functional disability (Katz Index, Lawton and Brody Scales) were analyzed. Multiple analysis was performed using Poisson regression with robust variance. *Results*: 360 elderly people aged 65 years and over participated in the study. The prevalence of functional disability for Basic Activities of Daily Living was 21.4% while for instrumental activities it was 78.3%. Functional disability in basic activities was higher among elderly males (p=0.03) who had suffered strokes (p=0.00) and were frail (p=0.00), while for instrumental activities it was higher among older elderly persons (p=0.04); who were illiterate (p=0.00), had less than five years of schooling (p=0.02); had depressive symptoms (p=0.00) and were frail (p=0.00). It was lower among elderly persons who lived alone. *Conclusion*: A high prevalence of functional disability was identified among the elderly for instrumental activities of daily living, demonstrating the need for an effective and immediate approach by health professionals, who should employ preventive care in order to tackle this problem.

Keywords: Health of the Elderly. Activities of Daily Living. Functionality.

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INTRODUCTION

The process of aging of the population is a worldwide phenomenon that occurs slowly but gradually in developed countries but much more swiftly in emerging countries like Brazil[1]. With this expansion, the additional years of life should be analyzed from a qualitative standpoint, as it is essential to provide better health conditions for elderly people, so that they may experience an active, healthy and functional aging process, with regard to carrying out their needs, for as long as possible[2].

Functional capacity can be defined as a set of physical and mental skills that are essential for the unaided execution of activities of daily living. For elderly people, this issue means that they are capable of carrying out activities and making decisions within their daily routine. In contrast, functional disability represents the dependence of this individual on others when carrying out such tasks[3].

These tasks can be divided into three broad categories, namely: Basic Activities of Daily Living (BADL) which include basic activities such as self-care, as determined by health, work, leisure and self-knowledge; Advanced Activities of Daily Living (AADL), a set of leisure activities, independent of work pursuits, educational activities, social participation, which depend on personal motivation; and, finally, Instrumental Activities of Daily Living (IADL), which refer to the capacity to carry out more complex activities, and which are therefore linked to the independence of the elderly person, given that some independence is necessary for executing such activities. The IADLs are characterized by work and by social contact, including meeting up with friends and participating in the community at large[3,4].

As functional disability may reduce the degree of independence when carrying out basic and instrumental activities, it is important to investigate the impact that this condition has upon the general lives of elderly people and also upon the health services. Evaluating the functional disability of elderly people is extremely important, as it can provide a basis for providing high-quality care and social services[5].

The main purpose of the present study was to calculate the prevalence of functional disability in basic and instrumental activities of daily living among the elderly and to examine the social, demographic and self-reported health factors associated with this phenomenon.

METHOD

This cross-sectional design and analytic study was carried out at a Reference Unit for the Health of the Elderly (RUHE) for outpatient treatment, in the northern part of the Brazilian state of Minas Gerais. This region has low Human Development Indices (HDIs), similar to those of the Brazilian Northeast, the poorest and least developed part of the country. The region is also an area of serious and unique social vulnerability[6]. This means that even a city of medium size suffers certain specific conditions, suggesting a need for studies focused on their specific particularities.

The subjects participating in the study were elderly people aged 65 and over, who were undergoing treatment between May and July 2015. The evaluated group was selected based on unintentional convenience sampling, based on the needs being attended to, considering the difficulties of making a random selection.

For the calculation of the sample size, a level of significance of 5% was applied, which is equivalent to a confidence interval of 95% and a tolerable sampling error of 3%. This first estimate of sample size was increased by 20%, in order to explore adjusted associations between the independent variables and functional disability. The minimum number was 360 elderly people.

The population sample was created based on the following criteria for inclusion: age of 65 years old or over and be undergoing treatment at the RUHE concerned. The criteria for exclusion were: any disability or incapacity which, as appraised by the family, or any hearing impairment, as yet unremedied, that would prevent the understanding of the questions asked. Disability according to the appraisal of the family was taken as a plausible measure, in the light

of the complexity involved in the administration of a specific instrument for such an evaluation. In this case, before starting the interview, the data collection instrument was presented to the family, who then decided whether or not the elderly person was able to take part in the interview.

To carry out the multidimensional interview with the target public, the interviewers were trained and calibrated in advance (kappa ≥ 0.8). The data was collected at the RUHE in both the morning and the afternoon.

The instruments for data collection, as used for this paper, were based on similar studies[6,7] and were previously tested in a pilot study conducted at this same location, with 20 elderly people who were not included in the analysis. For data collection, the following instruments were used: the BADL (Katz index[8]) and IADL (the Lawton and Brody Scale[9]) scales; the Edmonton Frail Scale[10], including the Clock Drawing Test[11], which is part of this instrument; the Geriatric Depression Scale[12], and also a questionnaire applied to the elderly person containing several social, demographic, epidemiological and clinical variables.

The independent social and demographic variables were: gender; age group (aged between 65 and 79, and aged 80 or over); white or non-white skin, as self-described; relationship status (with or without partner); living conditions (alone or with partner, family or friends); level of schooling (up to 4 years of schooling, and 5 or more years of schooling); literacy (yes or no); monthly family income (up to one Brazilian national minimum wage – MW, and more than one MW).

Clinical aspects refer to: the presence of chronic and non-contagious illnesses as self-reported, checked by means of the application of a second questionnaire to the elderly person: *diabetes mellitus* (DM); heart disease; bone and joint disease, stroke); symptoms of depression, according to the point score on the Geriatric Depression Scale: ≥ 6 points or < 6 points[12]; records of falls; hospitalizations over the past year; and degree of frailty.

Frailty was evaluated using the point score based on the Edmonton Frail Scale - EFS[10], which includes factors as follows: cognition, state of health; functional independence; social support; use of medication; nutrition; general mood; urinary continence; and functional performance. These domains are divided into 11 items, and the entire scale has scores ranging from zero to 17 points. The Edmonton Frail Scale (EFS) considers the elderly person as not frail when the score is between zero and 4 points (inclusive); *vulnerable to frailty* when the score is 5 or 6 points; suffering *mild frailty* for scores of 7 or 8 points; experiencing *moderate frailty* for scores of 9 or 10 points, and having *severe frailty* as those with scores ≥ 11 points[10].

In this study, for data analysis, the results of the independent variable were separated into two levels: absence of frailty (final score ≤ 6) and presence of frailty (final score > 6).

Cognition was evaluated through the Clock Drawing Test (CDT), which is part of the instrument used for the evaluation of frailty. The interpretation of the CDT is based on a score from 0 to 5 points. Five points are awarded for a drawing of a perfect clock, with small deviations concerning the position and the spacing of the numbers acceptable; in contrast, a score of 0 is assigned to those who are unable to reproduce a drawing of a clock, and those who refuse to take the test[11]. The CDT was not included in the bivariate or multivariate analysis, due to the fact that its connection with functional disability is already well covered and described in specialist literature. The non-inclusion of this variable in the statistical model for analysis may allow the expression of variables as yet little explored, and which should be discussed.

Functional disability, a dependent variable, was defined based on the limitations of the BADL, which were measured by the Katz Index[8]. The limitations on the IADL were evaluated by the Lawton and Brody Scale[9], which includes more complex items of daily living. Based on the Lawton and Brody Scale[9], the elderly people are considered independent for IADL when they score 27 points, while those with 26 points or less are considered dependent in this regard[13].

The Katz Index establishes a point score ranging from 0 to 3 points. The elderly person is totally independent for BADL with a score of 0; one point is awarded to those who need the help of an accessory

(such as walking sticks, Zimmer frames, support on furniture) to carry out activities; a score of two points means that human help is essential for the elderly person to carry our his or her tasks; and finally a score of three for BADL shows that the person is fully dependent[8]. Both the BADL and IADL scores have been recommended by the Brazilian Ministry of Health, and have been validated and adapted for use in Brazil[13].

For the calculation of the statistical significance of this association, the Chi-squared (χ^2) Test was used. Prevalence ratios (PR) were calculated in order to investigate the existence of associations between different independent variables and functional disability. The adjusted prevalence ratios were obtained through multiple Poisson regression analysis with robust variance, considering the independent variables most strongly linked to functional disability in bivariate analysis (up to a level of significance less than 0.20). For the final analysis, a final significance level of 0.05 ($p<0.05$) was considered.

The information thus collected was analysed through the *Statistical Package for the Social Sciences (SPSS),* version 17.0 *(SPSS for Windows,* Chicago, USA). The variables with $p \leq 0.05$ were considered statistically significant.

This study was approved by the Research Ethics Committee of the Universidade Estadual de Montes Claros, under Opinion Statement No. 1,003,534, and all the participants signed a Free and Informed Consent Form (ICF).

RESULTS

A total of 360 elderly people were interviewed: 78.1% of these were female. The prevailing age group was 65 and 79 years old [the mean age was 75.14 years; (±7.6)]. A total of 58.6% of the sample were literate; however, 85.8% had a low level of schooling, of four years at most; 62.5% of the elderly people in the sample declared themselves as white; 68.1% had a family income of more than one Brazilian national minimum wage (MW), and 83.1% lived with a partner or some other family member.

A total of 21.4% of the elderly people exhibited some functional disability for BADL, while 78.3% suffered disability for IADL. The evaluation of cognition through the Clock Drawing Test (CDT) showed that 79.2% of the elderly people evaluated had some degree of cognitive decline.

The bivariate analyses performed for functional disability for BADL and IADL and the other variables, are shown in Table 1.

We identified an association at a level of 20% ($p<0.20$) between BADL and the other variables considered: gender; family configuration; symptoms of depression; stroke (CVA); falls; periods in hospital; and frailty. In the case of IADL, there were associations with level of schooling; family configuration; literacy (knowing how to read); age; presence of diabetes; symptoms of depression; and frailty (Table 1).

The prevalence of functional disability for BADL was greater among elderly men who had had strokes and were considered frail (Table 2).

Functional deficiency for IADL was greater among the elderly people of more advanced age; those who were illiterate; those with less than five years of schooling; those who showed symptoms of depression and those classed as frail; and lower among the elderly people who lived alone, when compared to those living with spouse, partner or family (Table 3).

Table 1. Bivariate analyses between degrees of dependence for BADL and IADL and independent variables, in elderly people receiving care at a Reference Unit for the Health of the Elderly (RUHE) (N=360) in the city of Montes Claros, Minas Gerais, Brazil, 2015.

Independent Variables	Basic Activities of Daily Living (BADL)		*p*-value	Instrumental Activities of Daily Living (IADL)		*p*-value
	DEP*	IND**		DEP	IND	
	n(%)	n(%)		n(%)	n(%)	
Gender			0.021			0.33
Male	24 (30.4)	55(69.6)		65(82.3)	14(17.7)	
Female	53(18.9)	228(81.1)		217(77.2)	64(22.8)	
Age			0.232			**<0.001**
Up to 79 years	54(19.9)	217(80.1)		201(74.2)	70(25.8)	
80 years and over	23(25.8)	66(74.2)		81(91.0)	8(9.0)	
Skin			0.813			0.121
White	28(20.7)	107(79.3)		100(74.1)	35(25.9)	
Non-white	49(21.8)	176(78.2)		182(80.9)	43(19.1)	
Marital Status			0,461			0.534
With partner	34(23.3)	112(76,7)		112(76.7)	34(23.3)	
Without partner	43(20.1)	171(79,9)		170(79..4)	44(20.6)	
Literacy			0,412			**<0.001**
Yes	42(19.9)	169(80.1)		148(70.1)	63(29.9)	
No	35(23.5)	114(76.5)		134(89.9)	15(10.1)	
Schooling			0,684			**<0.001**
5 years and over	12(23.5)	39(76.5)		23(45.1)	28(54.9)	
Up to 4 years	65(21.0)	244(79.0)		259(83.8)	50(16.2)	
Family configuration			0,011			<0.001
Lives with partner, family members of friends	71(23.7)	228(76.3)		242(80.9)	57(19.1)	
Lives alone	6(9.8)	55(90.2)		40(65.6)	21(34..4)	
Has own income			0.951			0.392
Yes	75(21.4)	276(78.6)		276(78.6)	75(21.4)	
No	2(22.2)	7(77.8)		6(66.7)	3(33.3)	
Category of family income			0.911			0.564
More than 1 Brazilian Minimum Wage (MW)	52(21.2)	193(78.8)		194(79.2)	51(20.8)	
1 MW or less	25(21.7)	90(78.3)		88(76.5)	27(23.5)	
Has *diabetes mellitus*			0.901			**0.181**
Yes	16(21.9)	57(78.1)		53(72.6)	20(27.4)	
No	61(21.3)	226(78.7)		229(79.8)	58(20.2)	
Heart problem			0.731			
Yes	18(22.8)	61(77.2)		65(82.3)	14(17.7)	
No	59(21.0)	222(79.0)		217(77.2)	64(22.8)	
Malignant tumour			0.713			0.126
Yes	4(25.0)	12(75.0)		15(93.8)	1(6.2)	
No	73(21.2)	271(78.8)		267(77.6)	77(22.4)	

to be continued

Continuation of Table 1

Independent Variables	Basic Activities of Daily Living (BADL)		*p*-value	Instrumental Activities of Daily Living (IADL)		*p*-value
	DEP* n(%)	IND** n(%)		DEP n(%)	IND n(%)	
Bone and joint disease			0.564			0.082
Yes	36(22.8)	122(77.2)		117(74.1)	41(25.9)	
No	41(20.3)	161(79.7)		165(81.7)	37(18.3)	
Osteoporosis			0.312			0.714
Yes	30(24.4)	93(75.6)		95(77.2)	28(22.8)	
No	47(19.8)	190(80.2)		187(78.9)	50(21.1)	
Stroke - CVA***			**<0.001**			0.071
Yes	20(52.6)	18(47.4)		34(89.5)	4(10.5)	
No	57(17.7)	265(82.3)		248(77.0)	74(23.0)	
Symptoms of Depression			0.012			**0.011**
None	39(17.3)	187(82.7)		157(69.5)	69(30.5)	
Present	38(28.4)	96(71.6)		125(93.3)	9(6.7)	
Falls			0.064			0.091
No	28(17.1)	136(82.9)		122(74.4)	42(25.6)	
Yes	49(25.0)	147(75.0)		160(81.6)	36(18.4)	
Hospitalization			<0.001			0.431
None	52(18.3)	232(81.7)		220(77.5)	64(22.5)	
One or more	25(32.9)	51(67.1)		62(81.6)	14(18.4)	
Frailty			**<0.001**			**0.001**
Not frail	15(7.9)	175(92.1)		119(62.6)	71(37.4)	
Frail	62(36.5)	108(63.5)		163(95.9)	7(4.1)	

*Dependent; ** Independent; ***Cerebrovascular Accident.

Table 2. Factors linked to functional disability for BADL among elderly people who have been assisted at the Reference Unit for the Health of the Elderly (RUHE) (N=360) in the city of Montes Claros (Multiple Analysis). Minas Gerais, Brazil, 2015.

Independent Variables	Adjusted PR*	CI 95%**	*p*-value
Gender			
Female	1		0.03
Male	1.08	1.00-1.17	
CVA***			
No	1		0.00
Yes	1.20	1.08-1.32	
Frailty			
No	1		0.00
Yes	1.24	1.16-1.32	

(*) PR: Poisson Regression, with robust variance; (**) CI: Confidence Interval; (***) CVA: Cerebral Vascular Accident.

Table 3. Factors linked to functional disability for IADL among the elderly people receiving care at the Reference Unit for the Health of the Elderly (RUHE) (N=360) in the city of Montes Claros (Multiple Analysis). Minas Gerais, Brazil, 2015.

Independent Variables	Adjusted PR*	CI 95%**	*p*-value
Age			
Up to 79 years old	1		0.04
80 years old or more	1.06	1.00-1.14	
Literate			
Yes	1		0.00
No	1.09	1.02-1.16	
Schooling			
5 years or more	1		0.02
Up to 4 years	1.22	1.12-1.34	
Family Configuration			
Resides with spouse, partner, family or friends	1		0.00
Lives alone	0.91	0.84-0.98	
Depression			
No	1		0.00
Yes	1.09	1.03-1.16	
Frailty			
No	1		0.00
Yes	1.22	1.15-1.30	

(*) RP: Poisson Regression, with robust variance; (**) CI: Confidence Interval.

DISCUSSION

The present study calculated the prevalence of functional disability for basic and instrumental activities of daily living among elderly persons treated at a Reference Unit for the Health of the Elderly (RUHE). In addition, it provides a discussion on the social and demographic factors inherent to the health of elderly people, which can impact functional disability.

The level of functional disability for BADL was 21.4%, similar to that of a similar study conducted in Uberaba, in the state of Minas Gerais, where 17.6% of elderly people had some limitations for the execution of these activities[4]. In the case of IADL, functional disability came to 78.3%, which was higher than the results found in separate studies carried out in 2010 and 2012 in the city of Uberaba, state of Minas Gerais, which found that 46.3% and 65.9% of the elderly people, respectively, suffered functional disability for the instrumental activities studied[4,14]. This fact could be due to the fact that IADL require greater physical integrity and cognitive skills than basic activities[15].

The decline of functional capacity, as a rule, can be linked to social and demographic variables[15], as shown in the present study. It was confirmed that functional disability for BADL was associated with the male gender, the presence of sequelae of strokes and frailty. With regard to IADL, there was an association with living alone, in which case lower functional disability was observed. Among elderly people of a more advanced age; with lower levels of schooling, who are illiterate, and who show symptoms of depression, a greater level of functional disability was observed.

In terms of the link between the male gender and greater functional disability for basic activities, gender issues should be considered, as due to cultural issues many men do not carry out or do not request help to perform basic activities which include domestic chores. Therefore, the more significant functional disability among males could be a result of social

and cultural issues, rather than just associated with functional decline. Other factors that may contribute to functional disability among men include a greater exposure to risk in jobs requiring greater effort; cigarette smoking; routine ingestion of alcoholic beverages – and, as a result, the occurrence of chronic illnesses[16,17]. A study carried out in Itajurú, in the Brazilian state of Bahia, found that most males showed functional disability for the execution of these activities[16].

Even though, in the present study, functional disability mainly affected men, it is more common in literature to find that women are more afflicted by functional disability[3]. This is due to the fact that aging occurs at different paces in men and women, as men are prone to more lethal diseases, such as cardiac ischemia, while elderly women normally acquire morbidities of lower mortality but which are chronic and may lead to functional disability. In addition, elderly women seek medical services more often, use more medications, and also show greater participation in health intervention plans[13].

Elderly people who have had strokes suffer functional disability for the execution of BADL. This result is similar to that found in Goiânia, in the state of Goiás[19]. This means that functional disability related to strokes can be explained by the fact that this event has motor and sense-based consequences in the individual person, which makes walking independently and carrying out basic tasks related to self-care a more complex activity[19].

Regarding the greater functional disability for IADL among elderly people of a more advanced age, this agrees with the findings of a similar study in the municipalities of Ilhéus (Bahia), Caratinga (Minas Gerais) and Nova Santa Rosa (Paraná)[20]. As age advances, functional capacity may decline, moving from more complex activities to less troublesome ones, considering that the capacity for carrying out a task requires the combination of different physiological systems[1]. The present study found no association between functional disability and BADLs. Different results were obtained in studies carried out in the city of Teresina (Piauí) and Montes Claros (Minas Gerais), both these studies found that age was indeed linked to functional disability, both for BADLs and IADLs[21,1].

In this investigation, elderly people who were illiterate and those with few years of schooling experienced functional disability for IADL, similar to the results of a multicentric research study, that interviewed elderly people in the municipalities of Rio de Janeiro, Juiz de Fora (Minas Gerais), Campo Grande (Mato Grosso do Sul) and Cuiabá (Mato Grosso)[22]. This is justified by the fact that instrumental activities demand, from the elderly person, a certain level of literacy, as they are harder to execute fully[22].

Schooling and literacy have an influence upon the cognitive decline of the elderly person, as can be seen in a research study that evaluated institutionalized elderly people in Araxá (Minas Gerais), showing that the elderly people with lower levels of schooling suffered greater cognitive loss, which has an effect on functional disability[23].

The depressive symptoms were linked to functional disability for IADLs, which confirms the results of a study performed in Montes Claros (Minas Gerais), which identified that elderly people with symptoms of depression suffered functional disability only for instrumental activities[7]. In this study, the presence of symptoms of depression was not linked to functional disability for BADLs. This contradicts the findings of a study carried out in the city of Santo Antonio de Jesus (Bahia), which showed functional disability both for BADLs and IADLs, among people who showed symptoms of depression[24]. The functional disability related to depressive symptoms is due to the fact that activities, especially instrumental ones, require more organization and articulation in their tasks, which also involves social interaction[24].

In terms of the configuration of the family unit, it was observed that functional disability for IADLs was more common among the elderly who lived with others. This result was similar to that of the study carried out in the municipalities of Ilhéus (Bahia), Caratinga (Minas Gerais) and Nova Santa Rosa (Parana), which observed that the elderly people only had functional disability for IADLs[20]. Literature also reveals that those elderly people who lived with relatives, especially when the family unit brings together several generations, show a greater possibility of showing a decline in functional capacity

for the accomplishment of IADLs. As a possible explanation for this fact, we can mention the fact that these elderly people are often exempted from carrying out tasks that demand a greater level of complexity[20]. In other words, there may not be functional decline, but rather limited autonomy.

In the present study, frailty was a key factor in establishing functional disability, both for BADLs and IADLs. This association between frailty and functional disability is similar to that obtained in a study carried out in the city of Curitiba (PR)[25]. One probable justification for this is the fact that the elderly person exhibits greater limitations when exercising daily tasks, meaning that there is an initial decline in more complex activities, which require greater skill for development. Later, however, the elderly person may demonstrate difficulty in carrying out tasks of self-care[25,26]. A study in the city of São Carlos (São Paulo) obtained different results, however, finding that frailty was associated only with IADLs[26].

It was found that the elderly people demonstrated a reduced cognitive performance, similar to the findings of a study conducted in the city of Embu das Artes (São Paulo), where it was observed that 69.9% of the elderly people evaluated obtained a negative result in the test. Failure in the CDT can also be affected by a low level of schooling, as there is a need for basic numeracy so that the clock can be constructed and the time may be read[27].

The relevance of the CDT lies in the appraisal of many different cognitive areas, including memory; verbal understanding; capacity of planning; visuoconstructional skills; praxis and visual-spatial function, and so may indicate changes in the function of the frontal and the temporoparietal lobes[28].

The present study contained certain limitation: notably that the transversal methodological delineation makes it more difficult to establish the causal link between functional disability among elderly people and the predisposing variables discussed in the study. In addition, the study took place in a reference unit for the health of the elderly, suggesting that the sample was convenience-based, which restricts the external validity of the research, as the results can only be applied to similar populations. In addition, the health information was self-reported by the elderly patients.

Even so, despite such limitations, this study provides a suitable sample size, as necessary for the adjustment of models of regression, and also employs standardized instruments, already adapted for Brazilian culture. Research studies with a cross-sectional methodology are necessary to support local public strategies, as they provide more flexible information and can contribute to the monitoring of the real health conditions of the population.

Greater knowledge of the profile of the elderly people receiving care at the study location revealed that many suffered functional disability for some activity. This shows the need for suitably qualified health professionals who are capable of using the instruments that classify the functionality of elderly people. This in turn can enable early intervention, so as to reduce the effects of functional disability upon the quality of life of this group.

CONCLUSION

Among the elderly receiving care at the Reference Centre for the Health of the Elderly, in Montes Claros, Minas Gerais, some determining factors for functional disability for Basic Activities of Daily Life (BADLs) were identified, namely the male gender and having suffered a stroke. In contrast, functional disability for Instrumental Activities of Daily Life (IADLs) was established by factors such as: being literate; having lived longer; evidence of symptoms of depression; and living with spouses, partners, families or friends. Finally, functional disability, both for Basic and Instrumental Activities, was also determined by the frailty exhibited among the elderly people evaluated. Some degree of cognitive decline was also seen among many of the elderly people.

It is therefore essential that health professionals employ their knowledge and fulfill their role when dealing with elderly people, making use of the available tools and care systems, so as to ensure autonomy in the full evaluation of this group, as well as applying interventions in situations that present a risk for the elderly person.

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Reflections on the perception of the elderly regarding happiness and money

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Abstract

Objective: To describe and reflect the possible relationships established by the elderly between happiness and money. *Method*: It is a qualitative, exploratory and descriptive research, carried out from a semi-structured interview with 19 elderly people, in their households, of both sexes in 2017 and 2018, in two states of the South region of Brazil, through content analysis. *Results*: What emerged in the voice of older people unfolded into two categories: Money as a way of life and Money does not bring happiness. Participants indicated relationships between happiness and money because money is one of the conditions to meet the basic needs of daily life, but it appeared as a propedeutic resource for happiness. They also reported that the obsessive pursuit of money can generate fascination, anxiety and depression. *Conclusion*: The participants indicated that money is a means to live well and be happy and was not considered the highest goal of their lives. He is not a promoter of happiness, but can contribute to the pursuit of peace, tranquility and inner satisfaction.

Keywords: Happiness. Financial Support. Health of the Elderly.

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INTRODUCTION

According to authors such as Hadot[1], Lenoir[2] and Ferry[3,4], Western philosophical thought regarding happiness began with the Greeks. The precursor to such thought was Socrates, who asked the following existential question to humanity: What does happiness consist of? This classic question, which is relevant once again, was one of the core issues of ancient and mediaeval teleological ethics. These areas are considered teleological as they identify happiness as the supreme asset of humankind, "which has a purpose in itself". In other words, according to Aristotle, it is the most important goal that people seek in life, as demonstrated in an article in *Science* magazine, that to which all actions are directed, as the love of wisdom is "an intellectual activity inseparable from the activities of life"[3]. Nowadays, however, the discussion of happiness has been considered through different perspectives within the realm of philosophy.

Therefore, if the supreme asset of mankind is happiness, what exactly is a happy life? For Greek and Roman thinkers, especially Aristotle and Seneca[1,4], external assets, including money and also body-worshipping, produce a simple form of happiness, as they are actually means to something. It is interior assets, such as self-knowledge, as well as personal and social accomplishment, that generate most happiness[2].

From Kant[2], with the advent of the Enlightenment, Republicanism and secularity, both consecrated by the French Revolution, non-religious moral thought comes into being. In such thought, the essential purpose of mankind was no longer happiness in itself, but emancipation and freedom. Work is revalued, but no longer restricted to slaves and servants, but extended to all social classes.

Beginning in 1960 in the USA and 1980 in Europe, especially in France, "the issue of individual happiness has returned with strength"[2]. Recent philosophers, including Pierre Hadot, Michel Foucault, André Comte-Sponville and Luc Ferry, "have dared to reinsert and rethink the issue of happiness"[2]. According to Ferry[4], there has been a reawakening of happiness in the West, and we now have "an unprecedented proliferation of books with philosophical pretenses regarding happiness, inspired by ancient wisdom, Buddhism, Taoism and stoicism".

Happiness comprises a number of characteristics. Due to the sheer complexity of the concept, it is well-nigh impossible "to define it in a categorical and satisfactory manner"[4]. In general, some studies regard the concept, even among the elderly, as a state of satisfaction, health, care, morals, success, and also physical, psychic and spiritual well-being. It is connected to quality of living, security, freedom of choice, autonomy, healthy aging, intelligence, knowledge, functional capacity, love, emancipation, creativity, admiration, action[2,4]. In addition, we also see family relations, friends, playing with grandchildren and financial resources, as promoters of happiness.

Nowadays, happiness is much more closely based on seeking performance, in the production of goods and services, through work and study. "The world is now configured around money, and it is through this that national and international commercial transactions are made", based on a materialist and productivist nature, also taking into account human relations and assuming the characteristic of "disposability"[5].

In this competitive paradigm, companies, institutions and societies become hostages of a globalized capitalist market system. This way of life "ends up becoming a great deal of effort and competition, to obtain money and survive". Anyone who does not fit in this system of social and financial organization "will not make money or have a successful career and, as a result, will not be happy"[10]. Money is an object of economic studies, but is also addressed by sociology and psychology. This is the study of "the process of production, distribution, circulation and the consumption of wealth".

A study by Sumngern et al.[7] gets somewhat close to the concept of happiness structured on the properties of the soul. These authors proved that elderly people who did not need to work to survive considered themselves happier than those who were working and needed the money. Another study carried out with elderly people in rural areas of Chile also shows that there is a close relationship between happiness,

health, and money, as improved financial conditions allow the possibility of producing and feeding oneself in a more healthy manner, with independence, health and social participation, thereby enabling a healthy process of aging[12].

A study by Marques, Sánchez and Vicario[13] with 48 elderly people in Portugal, focusing on the perception of quality of life, found under the element of economic conditions that money does not occupy a central role within the lives of such individuals and has a kind of supporting role. Subjective well-being and quality of life, however, are factors that are essential to promoting happiness. Thus, the relationship between "economy (or, depending on one's understanding, money) and happiness is something that is historically established, being in the very genesis of this word and its attributes"[2].

The objective of the present study was therefore to describe and reflect upon the possible relationships between money and happiness as established by the elderly.

METHOD

This is a qualitative, exploratory and descriptive research study, conducted through interviews, with the application of a social and economic questionnaire with semi-structured questions, amongst a sample of 19 elderly people of both genders, selected through intentional sampling and interviewed at their homes, in two states of the south of Brazil. The interviews were carried out in 2017 and 2018 and lasted approximately 15 minutes each. In intentional sampling, the researcher chooses the participants by convenience and controls the selection thereof, to ensure that they make a significant contribution, according to the ultimate goal of the research project[14]. The sample size was defined based on the saturation of the information thus collected, and elderly persons who lived near the border between the two states studied were selected. The criteria for inclusion were as follows: independent elderly people aged 60 years or older, regardless of their social, cultural or financial conditions.

The questions guiding the interviews were: 1) As you see it, is money just a means, or the main goal of your life?; 2) Does money bring you happiness?; 3) What are the reasons why money brings, or does not bring, the happiness you desire? The answers were recorded and then transcribed for later analysis.

The information was then qualitatively analyzed, making use of Bardin's content analysis[15], through a skim reading in the pre-analysis stage, exploration of the materials, and interpretation, and grouped based on inference, during extraction of the units of significance and the drawing up of thematic categories, based on semantic criteria which are, in turn, based on the goal of the study. The participants are coded by the letter P, for participant, followed by an Arabic numeral that corresponds to the order in which the interviews were carried out.

The study is a result of the research project entitled *Razões da felicidade na longevidade* (Reasons for Happiness at an Advanced Age), linked to a *stricto sensu* Course in Human Aging, and approved by the Ethics Committee at the University of Passo Fundo (*Universidade de Passo Fundo* - UPF), Passo Fundo, Rio Grande do Sul, Brazil, under statement No. 898,152, according to the Resolution No. 466/12. The elderly persons took part in the study subject to the signing of a Free And Informed Consent Form.

RESULTS AND DISCUSSION

A total of 19 elderly people were interviewed, with ages ranging from 60 to 90 years, with a mean age of 69.5 years. 13 of the elderly people in this sample did not finish primary school; three did not finish high school; one was a university graduate; and two had doctorates. Six of them lived in rural areas, and the rest lived in the city. The participants were retirees, but continued to work in their normal professional activities as rural agriculture workers, a manual worker, a primary school teacher, a university teacher, a nurse and a historian (Table 1). The discourses of the elderly people were then divided into categories: "Money as a means of living" and "Money does not bring happiness".

Table 1. Profile of participants: Gender, age, schooling, monthly income, and professional activities.

Participant (P)*	Gender (M/F)**	Age	Schooling	Monthly income in Brazilian Minimum Wages (MW)	Professional Activities
P 1	M	60	High School	5 to 10	Maintenance worker
P 2	M	69	Primary School not completed	1	Agricultural worker
P 3	F	67	Primary School not completed	1	Agricultural worker
P 4	F	67	Primary School not completed	1	Agricultural worker
P 5	M	75	Primary School not completed	1 to 2	Agricultural worker
P 6	M	90	Graduate	2 to 5	Pastor
P 7	M	60	Doctorate	10 to 20	University professor
P 8	M	62	Doctorate	10 to 20	University professor
P 9	M	69	Primary School not completed	1 to 2	Agricultural worker
P 10	F	67	Primary School not completed	1.5	Agricultural worker
P 11	M	78	Primary School not completed	1	Agricultural worker
P 12	F	70	Primary School not completed	1	Agricultural worker
P 13	F	66	Primary School not completed	5 to 10	Agricultural worker
P 14	M	78	Primary School not completed	1.3	Manual worker
P 15	F	71	Primary School not completed	1.3	Agricultural worker
P 16	F	69	High School not completed	1.3	Domestic help worker
P 17	F	76	Primary School not completed	1.3	Agricultural worker
P 18	F	66	High School not completed	1	Basic Education teacher
P 19	F	61	Primary School not completed	1.2	Domestic help worker

*Participant: P; **Gender: M: Male; F: Female.

Money as a means of living

Money was found to be a necessary element for living, as studying, working and planning to obtain it is part of the existential condition. According to the perception of the elderly people, it was not mentioned as being the main goal of life, as the most important objective to be achieved, but rather as a means, a path, an instrument through which one can live well and happily.

The following statements show this need to acquire and have money as a useful medium to make the most of things, to survive, but always based on limits and responsibility, without idolizing money, as the following statements show:

> "It is a part, but is not everything. Money helps, but does not bring happiness" (P1).

> "Money is a means through which we can live well, as nobody can live without money" (P6).

> "One must have limits with money. [...]. If you just think about making money, money and more money, and then, when you see it, you get turned upside down, it goes nowhere" (P9).

> "Money helps to buy what we need to live, [...] but is not the most important thing" (P10).

> "A certain sum of money is necessary, in order to live" (P12).

> "It is indeed important for life, but it is not everything. There is no point having money if you don't have health. Money alone does not bring happiness" (P15).

> "Money is useful for life" (P16).

> "Just to pay your debts" (P17).

> "I just need enough to travel and pay bills" (P18).

> "To survive" (P19).

These perceptions agree with the concepts behind ancient and mediaeval teleological forms of ethics, according to which money plays the role of a means for attaining happiness, in both the individual and the social sphere. The lack of money makes people unhappy[1]». However, Seneca and Aristotle considered that there was no need to have many assets, especially money, "because of the concerns that are inherent to wealth: fear of being robbed; much time devoted to management of one's assets; envy of others"[2].

So, if money is but a path to achieve happiness, what is happiness itself? In the opinion of thinkers such as Socrates and Plato, and more significantly Aristotle and Seneca, factors such as a perfect body, physical strength, material wealth, some loyal and dedicated friends, and of course money, are all things that are necessary in order to attain happiness. These are supportive qualities and thus bring a temporary feeling of happiness, an aspect which is confirmed by statements such as those described above. In contrast, interior and constitutional-based qualities, meaning those that promote a more long-lasting form of happiness, are the assets of the soul, including the practice of such virtues as courage, moderation, justice, friendship, wisdom, prudence, intellectual pleasure, knowledge, self-knowledge, self-control, participation in the community. These are the assets that are essential for happiness, because true happiness comes through conscience. They promote calm, peace, and the imperturbability of the spirit, qualities which can be achieved through contemplation and meditation[1,2,4,9,16].

The participants also mentioned the meaning of money for specific purposes, which arise from the existential conditions of daily living, including leisure, health and nutrition:

> "One can live very well with money, such as go to parties for the elderly and have a beer" (P4).

> "Have money to survive and have some fun" (P9).

> "You need some money, to go out to parties with the family" (P5).

> "Money helps when you have to live and pay bills, and also to get something to eat. [...]. Now, having too much money and not knowing how to use it… this is something that really harms a person's life" (P11).

> "We need money to go shopping and to survive. (P14).

The study carried out by Lobos, Lapo and Schnettler[12], with 389 elderly persons in rural areas in central Chile, aged between 60 and 90, also showed that money has meaning, but as a means to achieve happiness. Health, government policies, nutritional satisfaction and social participation are all more important than money, confirming the hypothesis that, between health and money, health always takes priority. Similarly, a study by Angner et al.[17] also shows that being in good health is more significant than being well off.

Another issue that came up in the statements was the possible inconvenience that the lack of money can generate within the family and also at work, and how money should be used for budget planning and also in one's plans for life, albeit always in a balanced manner:

> "A lack of money always brings serious problems such as conflict within the family and ag work, among others. I received some good advice from my father, who said that money is not important. Money should be a consequence of your work, rather than the ultimate goal in life" (P8).

> "Money needs to be used based on careful planning, and sticking to a budget, with proper balance for our daily upkeep" (P6).

According to Lenoir[2], Seneca considered money to be necessary and useful. It allows one to invite friends over for dinner and to appreciate good wines, as also to commemorate and enjoy a lifestyle based on peace and calm in one's old age, arising from an existential plan lasting several decades.

The lack or shortage of money harms, and has direct interference upon, the family, personal, and social structures of the elderly, and also largely prevents access to better health, thereby reducing the likelihood of happiness, as the study by Lobos, Lapo and Schnettler shows[12].

Money does not bring happiness

Based on the statements of the elderly, money appears as a generator and a promoter of happiness and well-being, as an extrinsic motivator in working towards the accomplishment of projects of life. However, money did not emerge as a greater aim, a supreme goal, to which all other assets or goals of life are subordinate.

The following statements show that money should be used in a rational way, with care:

> "I always take care of it and like to have a bit of money" (P5).

> "It shouldn't be spent unnecessarily, as this brings worries" (P6).

> "However, there are some people who are enslaved by money. When they realise this, they are nearing the end of their lives and they leave the money behind. With me, things are different" (P10).

> "We wish for money if we don't have any, but health and our family brings more happiness" (P14).

This perception is backed up by recent theoretical and empirical studies. In the opinion of Lenoir[2], "it is certain that some money does indeed help to bring happiness, yet an incessant quest for wealth is just as harmful", because it leads to dependence and slavery. If money is used in a balanced manner, and not to excess, then extravagance and slavery would be avoided. Thus, there are sophisticated, intellectual, spiritual and ephemerous, vulgar and trivial pleasures that can be achieved through money and the fruition of material assets and the senses, always seeking happiness. Due to its utilitarian characteristics, this search becomes obsessive and compulsory, and "dominates our whole life"[4].

According to Marques, Sánchez and Vicario[13], what generates quality of life is not actually money or financial assets, but health, peace, harmony, happiness, and also the satisfaction of "keeping busy, whether with leisure activities, volunteering, or work itself. It also means maintaining good interpersonal relationships and getting support from one's family, friends and neighbors."

Sumngern et al.[7] carried out a study with 306 elderly people in Thailand to identify how happiness is perceived in different regions. Of elderly persons who lived in rural, suburban, and urban locations, 64.5%, 61.2%, and 22.8% respectively felt that their personal accomplishments or happiness were not satisfactory, or even poor, and had little motivation to live. On the whole, 12.4% considered their happiness levels to be good, 37.9% fair and 49.7% poor. Another finding of this study was that elderly people who did not work considered themselves happier than those who had to work and earn money in order to survive.

The participants in the present study identified money as a factor to promote happiness and satisfaction, and something essential to live in society, and also noted that a lack of money was a factor that generates conflicts and social destructuring.

> "Money brings happiness and well-being" (P9).

> "I just want enough money to live. I am happy with what I am earning" (P4).

> "Money does indeed play a part, and I feel that a lack of money can break up families, and also cause problems with work and one's social life" (P8).

These perceptions match the meaning attributed to money throughout history. According to Lauer-Leite[9], money has taken on a key role within the lives of people, institutions and countries, "especially as it is an instrument for mediation that makes it possible to meet human needs, as well as technological, economic and social development". The classic idea that time is money is still present nowadays. This view means that there is little time left to care for oneself, environmental issues, sustainability, and even happiness, because work, money and consumption are the ultimate goals in life[17]. However, global capitalism "has not managed to turn into goods the main asset that we all seek: happiness"[18].

A study with 870 people carried out by Ergin and Mandiracioglu in Turkey between 1990 and 2013[8] sought to identify the social and economic factors that determine health and happiness, and found a connection between financial means and happiness, supporting what was stated by the elderly people in this study. During this period, there were many crises in the country, especially in 2001, and in this year, the elderly people, especially those who were widowed or separated, and of lower income, reported lower levels of happiness and health. On the other hand, in years of prosperity greater tranquility, health, happiness, and motivation to live were observed.

Money was also mentioned, from a critical perspective, as an object of fascination and wonder, as a supreme asset to promote the consumerist festival of happiness, scheduled to fill in the existential void arising from the current crisis[2,4]. However, this search for having something ends up leading people into slavery:

> "For me, money has always been a commercial factor and a cause for fascination. As we are now in the twenty-first century, where there is a deep crisis of values and rational criteria, money has filled this space" (P7).

> "In capitalist society [...] money ends up enslaving us. People want to earn more, at any cost. For this reason, I feel that Brazil today, the Brazilian portrait of all this corruption, everything revolves around having, managing to get things easily" (P8).

> "But money does not bring happiness to anyone" (P2).

> "There are some people who just think about money, and forget about investing in their health to save money. Then comes greed, harming the person in the end" (P11).

> "Money does not leave anyone any happiness" (P12).

> "It's not worth having a lot of money, as it does not bring happiness"(P19).

These perceptions are directed at the consumist ideologies which, through money, ensure total, captivating and perennial happiness[19], but which, paradoxically, may breed disappointment and unhappiness, as they contribute little towards the achievement and maintenance of spiritual peace, "as the beautiful promise of happiness threatens to turn into the tyranny […] of "perpetual euphoria"[4]. Along these same lines, according to Lenoir[2], "we hesitate to write that money does not necessarily bring happiness" and, according to Pereira[5], this happiness produces fragmentation, even splintering relationships based on solidarity and friendship with others, "now based on subjectivism and materialism".

However, according to Matz, Gladstone and Stillwell[20], when the money spent on goods corresponds to the personalities of the consumers, it seems that money can indeed buy happiness, as these assets cause a more significant rise in happiness. However, it must be stated that none of the participants had this perception.

The elderly people also mentioned that, when money tries to fill the void created by this capitalist society, which is based on technology, it appears as a kind of fetish, in which people try to be independent, recognized through the consumption of certain brands:

> "And when money takes up this space, it enters what Marx and Benjamim have defined as fetishism. [...]. Money not only as something used to buy things, but also as a representation of the world. [...]. It is the brand that shall define people, and what comes along, traced by this money" (P7).

> "Society gives great value to money. Capitalism, this need to buy, is very strongly present in young people" (P8).

The fetish leads people to identify themselves with certain brands of products and services, becoming mercantilist[21], strongly tied to the concept of having something, of consumption, as, "according to neoliberal capitalism, happiness lies in uncontrolled hypercapitalism"[22]. According to Bauman[23], this is the concept of I owe money, therefore I am, the art of living in debt, meaning that the ideal person for banks and credit cards is the 'ideal debtor', 'who never pays his or her bills in full".

In other statements, the elderly people say that economy, and attachment to money, is not convenient as it may produce suffering, and does not help to promote tranquillity and quality of living:

> "It is stupid to want to save money" (P2).

> "We must not attach ourselves to money" (P9).

> "Many years ago, this greed, this wish to have more, was not so important. People were happy with less, but society has evolved, or 'regressed', and now we have a lot of stress and depression" (P8).

> "It is a problem when we have too much money. We are happy with what little we have" (P12).

> "A lot of money is not good for you. It gets in the way" (P13).

> "For me, it is not everything" (P14).

According to Ferry[4], as happiness is something complex that cannot be defined, due to the human condition based on a constant search for progress and accomplishment, "we can never be absolutely sure about what makes us happy on a long-lasting basis – money, love, social prestige, talent, erudition or knowledge: everything that brings us happiness may turn into its opposite". This is backed up by the comments made by the interviewees with regard to money, as the absence thereof leads to suffering in the light of human needs.

However, having money does not in itself suffice to bring happiness, especially as a central element of life, and can bring concerns and experiences that are not in keeping with a happy life. The search for peace, health, tranquility, quality of living, balance, and social participation are things that bring about accomplishment, a happiness that lasts for a longer period. Considering this fact, we suggest the expansion of the methodology of the present study, with discussion within focus groups, and also the establishing of links with subjective well-being and quality of life.

CONCLUSION

The results show that, within this relationship, money has shown itself to be a means and a propaedeutic for the promotion of happiness, internal accomplishment, for carrying out life plans and daily tasks. This perception agrees with the ancient and mediaeval teleological models of ethics, in which money, like external assets, cars, houses, capital and the like, was considered and valued as an extrinsic and auxiliary asset. What generates most happiness is in fact our interior assets: How to be virtuous, balanced, the search for knowledge, self-knowledge and internal satisfaction. This concept, defended by the philosophies of Aristotle, the Stoics and the Cynics, was, and continues to be, critically taken up by philosophers, particularly French philosophers such as Hadot, Ferry and Lenoir, considering the historical and cultural distance between the periods. Recent empirical studies with elderly people also confirm this classic view that money promotes a transitory happiness, which is necessary but not the main reason for existence. The elderly people in the present study also mentioned that the lack of money could indeed produce emotional, familial, and social imbalances, and that the obsessive search for money, due to one's fascination for possessing things, could generate suffering, avarice and depression.

In the light of these results, there is a need for further empirical studies, with a greater number of participants, to further explore the relationship between money and happiness among the elderly, as the thematic affinity is a complex issue. The overlap between these two issues supports the importance of studies of elderly people, whether due to the necessity of a long and happy life, or the common financial fragility of this population once detached from labor activities.

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Prevalence of dementia among widowed and non-widowed patients and associated clinical and sociodemographic characteristics

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Abstract

Objective: to verify if the prevalence of dementia differs between widowed and non-widowed elderly persons and between genders, and to analyse if there is an association with sociodemographic and clinical characteristics. *Method*: a retrospective cross-sectional observational study of patients treated at a Behavioral Neurology outpatient clinic from 1999 to 2009 was carried out, employing anamnesis, physical and neurological examination, the Clinical Dementia Rating Scale (CDR) and the Mini Mental State Examination (MMSE). Sociodemographic (schooling and age) and clinical (age of onset of symptoms and time since onset of symptoms, MMSE and CDR) variables were analyzed. The differences were evaluated by the Mann Whitney test, using a significance value of $p<0.05$. *Results:* of 208 patients diagnosed with dementia, 73 (35.1%) were widowed and 135 (64.9%) were non-widowed. Those who were widowed were older than those who were non-widowed ($p<0.001$) when diagnosed with dementia. This difference in age remained when gender ($p<0.001$), widowed and widowed women ($p<0.001$) and widowed and non-widowed men ($p<0.001$) were compared. The time from onset of symptoms to diagnosis was greater in widowed than in non-widowed men [55.6 (± 86.3) vs. 43.4 (± 44.8) months], although the difference was not statistically significant. Widowed patients with dementia had lower schooling, regardless of gender ($p<0.05$). *Conclusion:* the prevalence of dementia differed between widowed and non-widowed individuals, being higher among non-widows. There was an association between widowhood and the clinical and sociodemographic characteristics, with differences between the genders. The loss of a spouse can generate different outcomes among men and women, necessitating measures with a specific focus on prevention and strategies of care in dementia.

Keywords: Dementia. Alzheimer´s Disease. Epidemiology. Widowhood.

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INTRODUCTION

The relationship between dementia and widowhood has been recently analyzed. Evidence shows that marital status can prevent the risk of dementia, through daily social interactions, together with the enhancement of cognitive reserves, the development of coping skills, and increased resilience[1].

Data suggests that marriage can result in greater social contact, which in turn can lead to a lower risk of developing dementia[2]. However, in contrast, the loss of a spouse can bring additional stress through grieving, and can therefore facilitate the occurrence of dementia[3].

Studies show that widowhood can indeed reduce stress, through a reduced burden upon the caregiver and the reduced exposure of the spouse to suffering, representing a factor of protection against forms of dementia[4]. Social relationships should be taken as a factor that brings considerable risk, and socially motivated interventions are factors that could provide an opportunity to reduce overall risk[5].

Even though there some studies have established a connection between dementia and widowhood, there remains a lack of evidence in specialized literature regarding the prevalence and the social and demographic profiles of those individuals, both widowed and non-widowed, as well as the impact of widowhood on different genders. The purpose of the study was to assess if there is a difference in the prevalence of dementia between widowed and non-widowed individuals; to consider whether there is any association with other social, demographic and clinical characteristics and, at the same time, verify if there are any differences between the genders.

METHOD

All individuals involved in the study were evaluated at the Behavioral Neurology Sector of the Universidade de Santo Amaro, in the city of São Paulo, São Paulo state, Brazil. This study was accepted by the Research Ethics Committee under registration number 128/2015. The patients who were treated at this outpatient unit either sought treatment, or were referred due to cognitive disorders or behavioral disorders which suggested some type of neuropsychiatric disorder. As a criterion for inclusion, cases with first diagnosis of dementia as defined on the medical records were accepted. Patients with other types of cognitive disorder were excluded, as well as those who did not meet the criteria adopted for the definition of dementia.

A cross-sectional observational study was performed based on the analysis of 297 medical records, selected based on one sole criterion, that of being duly completed and containing comprehensive information about patients who had received outpatient treatment between 1999 and 2009, corresponding to the period over which the proposed services were provided. The individuals selected for appraisal were part of the Behavioral Neurology Department of the Universidade de Santo Amaro, and were served by public health services in the Greater São Paulo metropolitan region. The treatment and the collection of information were both performed by the same neurologist, and the cognitive and functional analysis was performed through the Mini Mental State Exam (MMSE) and also through the Clinical Dementia Rating Scale (CDR), applied by a psychologist specializing in neuropsychology[6,7]. The data was analyzed to see if there was a difference between the number of patients with dementia, between the two groups considered (widowed and non-widowed), considering social and demographic (schooling and age, respectively) and clinical variables (age at onset of symptoms, time since onset of symptoms, MMSE and CDR) variables. There was also an appraisal as to whether there was any social, demographic or clinical differences between men and women, considering both widowed and non-widowed individuals, and if there was a difference in gender among widowed and non-widowed people with dementia. No distinction was made between single people, those living with a partner, and those who were separated. To appraise dementia and differences between genders, the sample was divided into two groups: women with dementia and men with dementia. In addition, there was a separate analysis of differences between the genders based on the comparison of widowed and non-widowed women, as also between widowed and non-widowed men.

The diagnosis of dementia was based on the criteria set out in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-lV)[8]. The clinical diagnosis was made according to the following published criteria: Those of the *National Institute of Neurological Communicative Disorders and Stroke–Alzheimer's Disease and Related Disorders Association* (NINCDS-ADRDA) for Alzheimer's Disease[9], and of the *National Institute of Neurological Disorders and Stroke – Association Internationale pourla Recherche et L'Enseignement en Neurosciences* (NINDS-AIREN) for vascular dementia (hereinafter DV)[10].

The Mann-Whitney test was applied to compare the groups with and without dementia, according to their gender and widowhood status. The Mann-Whitney test was also performed for each of the following variables: age; age at onset of symptoms, time since onset of symptoms (in months), schooling (in years), MMSE and CDR. For statistical analysis, a specific statistics programme was used. The level of significance was set at $p<0.05$.

RESULTS

A total of 208 (70.03%) patients with dementia and 89 (29.96%) without dementia were identified. The group of people without dementia included those with a diagnosis of subjective cognitive impairment and those showing some kind of psychological or psychiatric disorder; however, the diagnosis was not defined. Of the group with dementia, 73 patients (35%) were widowed, while 135 (65%) were not. It was found that widowed patients with dementia were older ($p<0.0001$) and had a lower level of schooling ($p<0.0001$), than those who were not widowed (Table 1).

In relation to gender, women with dementia tended to be older ($p<0.0001$) and have a lower level of schooling ($p=0.0008$) than men (Table 2).

In addition, widows were older ($p=0.0001$) and had a lower level of schooling ($p=0.0387$) (Table 3). Similarly, widowers tended to be older ($p=0.0005$) and have a lower level of schooling ($p=0.0340$) (Table 4).

Table 1. Difference between widowed (n=73) and non-widowed patients (n=135) living with dementia. São Paulo, SP, 1999-2009.

Variables	Widowed Mean (±SD)	Not widowed Mean (±SD)	Widowed x Not-Widowed *p*
Age	78 (± 12)	67 (± 10)	<0.0001
Schooling (years)	1.89 (± 2.53)	3.54 (± 3.52)	<0.0001
Age at onset of symptoms	74.3 (± 8)	69.3 (± 12.9)	<0.0001
Time since onset of symptoms (months)	46 (± 48.5)	43.1 (± 58.1)	0.2169
Mini Mental State Exam	10.5 (± 7.67)	14.7 (± 9.24)	<0.0001
Clinical Dementia Rating	2.12 (± 0.74)	1.91 (± 0.81)	0.0446

The *p* value refers to the Mann-Whitney test. SD = Standard Deviation.

Table 2. Difference between women (n=98) and men (n=110) living with dementia. São Paulo, SP, 1999-2009.

Variables	Women Mean (±SD)	Men Mean (±SD)	Women x Men *p*
Age	75.3 (± 9.7)	67.5 (± 13)	<0.0001
Schooling (years)	2.1 (± 2.5)	3.7 (± 3.7)	0.0008
Age at onset of symptoms	71.6 (± 9.9)	63.9 (± 13.3)	<0.0001
Time from start of symptoms (months)	44.2 (± 31.2)	44.3 (± 33.3)	0.3893
Mini Mental State Exam	10.8 (± 6.6)	15.3 (± 7.5)	<0.0001
Clinical Dementia Rating	2.17 (± 0.77)	1.81 (± 0.76)	0.0018

The *p* value refers to the Mann-Whitney test. SD = Standard Deviation.

Table 3. Difference between widows (n=58) and non-widowed women (n=40) living with dementia, São Paulo, SP, 1999-2009.

Variables	Widows Mean (±SD)	Non-widowed Mean (±SD)	Widows x Non-widows *p*
Age	78.3 (± 7.4)	70.4 (± 10.5)	0.0001
Schooling (years)	1.83 (± 2.51)	2.53 (± 2.53)	0.0387
Age at onset of symptoms	74.9 (± 7.4)	66.8 (± 11.1)	0.0002
Time since onset of symptoms (months)	43.3 (± 33.3)	42.5 (± 64.3)	0.0588
Mini-Mental State Exam	10.2 (± 6.4)	11.9 (± 7.1)	0.1000
Clinical Dementia Rating	2.25 (± 0.74)	2.05 (± 0.81)	0.1325

The *p* value refers to the Mann-Whitney test. SD = Standard Deviation.

Table 4. Difference between widowers (n=15) and non-widowed men (n=95) living with dementia, São Paulo, SP, 1999-2009.

Variables	Widowers Mean (±SD)	Non-widowed men Mean (±SD)	Widowers x Non-widowed men *p*
Age	76.6 (± 8.95)	66.2 (± 13.28)	0.0005
Schooling (years)	2.20 (± 2.67)	3.98 (± 3.78)	0.0340
Age at onset of symptoms	71.9 (± 9.9)	63.2 (± 13.5)	0.0043
Time since onset of symptoms (months)	55.6 (± 86.3)	43.4 (± 44.8)	0.3248
Mini-mental state exam	11.6 (± 5.4)	16.0 (± 7.7)	0.0120
Clinical Dementia Rating	Not evaluated	Not evaluated	Not evaluated

The *p* value refers to the Mann-Whitney test. SD = Standard Deviation.

With reference to the clinical variables, it was found that widowed patients living with dementia tended to have been older when the symptoms started ($p<0.0001$), have lower MMSE scores ($p<0.0001$) and also higher CDR scores ($p=0.0446$). There was no statistical difference in the time since the onset of symptoms ($p=0.2169$) (Table 1). In terms of gender, women living with dementia tended to be older at the onset of symptoms ($p<0.0001$), have lower MMSE scores ($p<0.0001$) and a higher CDR ($p=0.0018$). There was no statistical difference in time since onset of symptoms (p=0.3893) (Table 2). Widows living with dementia were also older at the onset of symptoms than non-widows ($p=0.0002$), but there was no statistical difference in time since onset of symptoms ($p=0.0588$), MMSE score ($p=0.10$) and CDR ($p=0.1325$) (Table 3). Widowers were older at the onset of symptoms ($p=0.0043$) and had a lower MMSE score ($p=0.0120$). There was no statistical difference in time elapsed since onset of symptoms ($p=0.3248$) and CDR was not appraised in widowers, due to a lack of sufficient data in the medical records (Table 4).

DISCUSSION

According to the present study, people living with dementia were generally older than those without dementia, when both genders were considered together. A metanalysis published in 2018 showed that widowed people had a 20% higher risk of developing dementia than married people, in studies duly adjusted for age and gender[11]. These results were found in studies where dementia was diagnosed based on the clinical examination on all participants, rather than through analyses of data collected from information gathered through routine collection. This study found a greater risk of dementia developing among widowed people, in case-control

and cross-sectional studies, compared with cohort studies[11]. These results confirm the findings of the present study, which exhibited a greater occurrence of dementia among widowed people, which links widowhood to greater conditions of stress and less social support for dealing with daily activities[12].

The loss of a spouse is considered one of the most stress-inducing events that a person can face. Widowed individuals exhibit a greater risk of psychological disorders, and also higher mortality, than married people[13]. A study showed a lower risk of dementia among widowed people, compared with other categories of marital status, including unmarried, single, and divorced; however, the duration of the study was not deemed sufficient to evaluate these differences. According to the present study, social and economic factors can contribute to the differences between the genders, in combination with marital status, among cases of people living with dementia[14].

It was found that widowed patients living with dementia tended to be older than non-widowed patients (Table 1). This agrees with a recent study which showed that, as time elapsed after the death of a spouse, there is a significant acceleration of the process of cognitive decline, thereby strengthening the concept that widowhood increases the risk of cognitive impairment among older individuals[15].

Level of schooling was higher among non-widowed people than widowed people living with dementia (Table 1). According to cognitive reserve theory, level of schooling and other exposures that occur throughout life, such as mental and social activities, provide alternative cognitive operations or neural networks of greater efficiency, which enable individuals to better handle brain damage, thereby delaying the onset of dementia[16]. These results agree with the data of previous studies that appraised the beneficial effects of marriage upon cognitive reserve and found that the resilience of the relationship is responsible for a lower occurrence of neuropathological damage[17]. In contrast, another study showed that caregivers may remain, or become, resilient over time, in spite of the deterioration of health, institutionalization and death of the respective spouse. This being the case, widowhood cannot always be seen as a barrier to resilience[18].

The age at the onset of symptoms was higher in widowed patients living with dementia than non-widowed patients living with dementia (Table 1). This adds weight to the theory that a patient may delay seeking medical care when he no longer has a spouse to note his symptoms. As the number of widows was greater than the number of widowers, it is possible that women may seek health care only in more advanced stages of dementia, even after the death of the spouse, resulting in a more advanced age at the onset of symptoms, than in non-widowed women with dementia.

Regarding MMSE and widowhood, widowed patients with dementia had lower scores than non-widowed patients with dementia (Table 1). These results suggest that a marital status of widowed is associated with worse cognitive performance. A study that appraised cognitive decline through the MMSE showed that being single or widowed increased the likelihood of cognitive decline, with a greater impact among men, a result which matches the findings of the present study (Table 4)[19].

The CDR values were higher among widowed people with dementia than non-widowed people living with dementia, which also suggests that the severity of the dementia is greater among widowed individuals (Table 1). There is evidence that the greater severity of dementia among married people has been favorably associated with total duration of care. However, there is a dearth of studies evaluating this kind of measure among widowed people[20].

In the present study within the group of patients living with dementia, women dementia patients tended to be older than men dementia patients, a fact that agrees with other previous studies, showing that women have a longer survival period, and are also diagnosed at more advanced stages of the disease than men (Table 2)[21]. In addition, women had a lower level of schooling, lower MMSE score, and higher CDR score (Table 2). It is known that dementia affects women disproportionately in comparison to men, and so health care providers should provide a better response to patient needs[22]. This could be linked to the fact that female caregivers also need to take on new activities that in the past were carried out by the individuals with dementia,

thereby contributing to an increase in stress and also burden among these women[23]. Most of these are adult daughters or spouses of patients living with dementia, aged over 65, which makes the tasks of caring more difficult. In addition, women tend to spend more time on care activities than men[24]. The reasons for this are many, but one possibility could be that women are less likely to work outside the home[24,25]. Another feasible explanation is that women more often end up being caregivers due to the cultural expectations placed upon them. The fact that men with dementia are younger at the onset of symptoms, as well as having a greater MMSE score and lower CDR score, could be linked to greater care provided by their spouses, a fact which would lead men to seek treatment more quickly, after cognitive disorders were observed.

When analysing the social and demographical variables separately by gender, it was found that both widows and widowers were older and had a lower level of schooling than non-widowed men and women, with the greatest difference observed among widowers (Table 3 and 4). Age at onset of symptoms was greater in both widowed men and women; however, MMSE was only different in men, with widowers achieving lower scores. This result agrees with another study that reveals the greater impact of widowhood among men (Tables 3 and 4)[19]. There was no difference in CDR scores between widowed and non-widowed women. It was not possible to evaluate this variable among men, due to the lack of sufficient data in medical records (Tables 3 and 4).

The present study had some limitations. As it is a retrospective study, no statistical corrections for age or level of schooling were made. In addition, as the differences between specific marital statuses were not considered, there is a possibility of methodological bias, as people who were single, separated, or living with a partner do not necessarily have the same characteristics as married people.

CONCLUSION

The present study found that the prevalence of dementia was different between widowed and non-widowed people, being higher among non-widowed individuals (65% of cases). There was a link between widowhood and other social, demographic and clinical characteristics, showing that widowed people living with dementia tended to be older and have a lower level of schooling than the non-widowed. Widowed patients were older at the time of the onset of symptoms, and had a higher CDR score, as well as lower MMSE score, than non-widowed patients. There was no statistical association between widowhood and the time elapsed since the start of symptoms.

There was also a certain degree of association in terms of gender, with women living with dementia having a more advanced age and poorer levels of schooling than men. Women were also older at the onset of symptoms and had lower MMSE scores and greater CDR scores than men. There was also no statistical association with time since onset of symptoms, in this case.

When analysing gender in isolation, it was found that both widows and widowers were older and had a lower level of schooling. In addition, widows and widowers were older at the onset of symptoms than non-widowed patients. There was only a difference in MMSE scores among men, with widowers having a lower score than widows. Differences were not observed in either CDR scores or time since onset of symptoms.

These differences clearly suggest a need to evaluate the impact of widowhood on widows and widowers with dementia, as the loss of a spouse can result in different outcomes. It also warns of the need to adopt health measures with a special focus, with the aim of achieving more effective prevention in cases of dementia, as well as early diagnosis and more appropriate and more efficient health care strategies.

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Social support for the elderly with HIV/Aids: an integrative review

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Abstract

Objective: The present integrative literature review aimed to verify the scientific knowledge produced about social support for elderly persons with HIV/Aids. *Method*: A search was carried out in the Lilacs, Medline, Scopus and Web of Science databases for studies published in the last ten years. The final analysis consisted of seven articles. *Results*: It was found that social support is extremely important in the life of the elderly with HIV/Aids, and a real need for this support was identified. Such support can both contribute to quality of life in many ways, as well as impair the care of those who live with the disease, as the diagnosis, treatment and the entire stigma surrounding this chronic condition directly influence the type and quality of support provided. *Conclusion*: It is hoped that the results of this review will contribute to are flection on health practices for the elderly with HIV/Aids.

Keywords: Elderly. Social Support. Acquired Immunodeficiency Syndrome.

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INTRODUCTION

The population aged 60 and over in Brazilian society is growing rapidly. At the same time, fast-moving advances in medicine and technology are allowing people to grow older in a healthier way, with a better quality of life. This includes prolonging sexual activity through facilitators of modern life, such as hormone replacement and impotence drugs. These facilitators help the elderly to rediscover experiences, including sexuality, making their lives more enjoy able yet more vulnerable, and requiring investment in prevention campaigns against sexually transmitted infections (STIs), especially AIDS[1].

The aging of the HIV epidemic has brought new challenges related to both diagnosis and the link between the elderly person and the proposed therapeutic approach, in the hope of achieving greater adherence to and connection with treatment, while not overlooking issues such as human rights, mutual respect and inclusion. The overall population is aging and the increase in HIV prevalence among the elderly is related to the fact that people can contract HIV at more advanced ages through unprotected sex, as well as the greater life expectancy of people who have been living with HIV since before the age of 60[2].

Recent data from the 2017 Epidemiological Bulletin on AIDS and STI from the Ministry of Health indicate that in 2016, when 1,294 HIV cases were registered, there was a 15.0% increase in the number of people aged over 60 with the virus in comparison with the previous year. In 2015, meanwhile, the numbers were 51.16% (1,125 people infected) higher than in 2014, when 856 people were diagnosed with the virus[3].

Receiving a positive diagnosis of HIV represents a significant event, triggering reactions and a combination of negative feelings linked to ideas of death/finitude. It is a serious concern that greatly affects the physiological and psychological systems of both those with the disease and their families, who are directly involved in the care of the sufferer, whether through social, religious, ethical or moral impacts[4].

In the 2015 study by Silva, the reactions of the elderly to a diagnosis of HIV positive involved fear of death and disability, and notably that the diagnosis, which is considered shameful, would be revealed to family, friends and others from the patient's social network, causing embarrassment, rejection, discrimination and distancing from others. HIV-related stigma and prejudices have a number of negative consequences in the battle against AIDS, both for people living with HIV and for prevention strategies[6].

HIV/AIDS in the elderly has effects that can lead to changes in their identities, experiences, and a remodeling of their being and situation in the world. AIDS-related prejudice is still with us, taking its toll on people living with HIV in terms of suffering, isolation and loneliness, notably because such discrimination often comes from relatives and those closest to the sufferer, restricting their support network, which has consequences for the positive coping with the disease[7].

According to Silva[8], social support networks are hierarchical groups of people who maintain links between one another, typically of relationships in which they give and receive support, and places that usually provide material help, services and information, such as allowing people to believe they are cared for, loved and valued in times of need and ensuring that they belong to a network of common and mutual relationships. Social support is important insofar as it corresponds to the needs experienced by the elderly themselves. Within this perspective, social support includes a broad network of emotional, informational and instrumental support.

Thus, the need for listening, attention, information and esteem is established as fundamental, influencing different attitudes towards HIV/AIDS, both in the diagnosis and during the course of the disease, depending on the social support received by the elderly. The aim of the present study was therefore to carry out an integrative review of literature, seeking scientific evidence about social support for the elderly living with HIV/AIDS.

METHOD

The present study comprised an integrative review of literature, systematically gathering and synthesizing the results of research on a given topic,

allowing the incorporation of the evidence in clinical practice[9]. The study was carried out based on the following steps: 1) Definition of the theme and elaboration of the guiding question; 2) Selection of the electronic databases used in the research; 3) Establishing of inclusion and exclusion criteria; 4) Definition of descriptors; 5) Pre-selection of articles; 6) Evaluation of the articles that made up the sample; 7) Interpretation of results and 8) Presentation of the integrative review[10].

The following guiding question was applied: what scientific evidence has been published in the last 10 years that addresses social support for the elderly with HIV/ AIDS? Articles were selected from four databases: Latin American and Caribbean Literature in Health Sciences (or LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE), SCOPUS and WEB OF SCIENCE. The articles were collected between May and June 2018. Descriptors in Portuguese and English were taken from the Health Sciences Descriptors (or DeCS) of the Virtual Health Library (HIV, AIDS, social support and the elderly) and the Medical Subject Headings (MeSH) of the National Library of Medicine (HIV, Acquired Immunodeficiency Syndrome, Social Support and Aged), combined with Boolean operators. In the LILACS search, the search key "HIV or AIDS and SOCIAL SUPPORT and THE ELDERLY" was used. In MEDLINE, SCOPUS and WEB OF SCIENCE the following combination was used: "HIV or ACQUIRED IMMUNODEFICIENCY SYNDROME and SOCIAL SUPPORT and AGED".

The inclusion criteria were: complete articles available electronically in any language, published in the last 10 years and that cover the theme of social support in the elderly with HIV/AIDS. The exclusion criteria included review articles, dissertations, theses, letters to the editor, technical guidelines, expert opinions and books. Repeated articles were considered only once.

Once selected, the articles were read and analyzed in an organized manner to evaluate the rigor and characteristics of each study, observing their methodological aspects, intervention or proposed care, result, conclusion and level of evidence. The instrument corresponded to the Hierarchical Classification of Evidence for the Evaluation of Studies, based on the categorization of the Agency for Healthcare Research and Quality (AHRQ), where the quality of evidence is classified into seven levels. According to the eligibility criteria, the levels of the Hierarchical Classification in the present study were: Scientific evidence from randomized controlled clinical trials, well-delineated clinical trials without randomization, cohort studies and well-delineated control cases and scientific evidence derived from descriptive or qualitative studies[11].

Figure 1 shows the distribution of articles found and selected based on the inclusion and exclusion criteria. The great majority of the excluded articles were removed due to the fact they did not approach the theme of social support in elderly people with HIV/AIDS, and when the theme of "social support" was addressed, it was in the pediatric or adolescent population.

RESULTS

After the exploratory reading of the 11 articles selected, seven articles were selected for inclusion in the integrative review, after which the hierarchical classification of the evidence for the evaluation of studies was performed, based on the AHRQ categorization.

The relevant information of the selected articles is described in Chart 1.

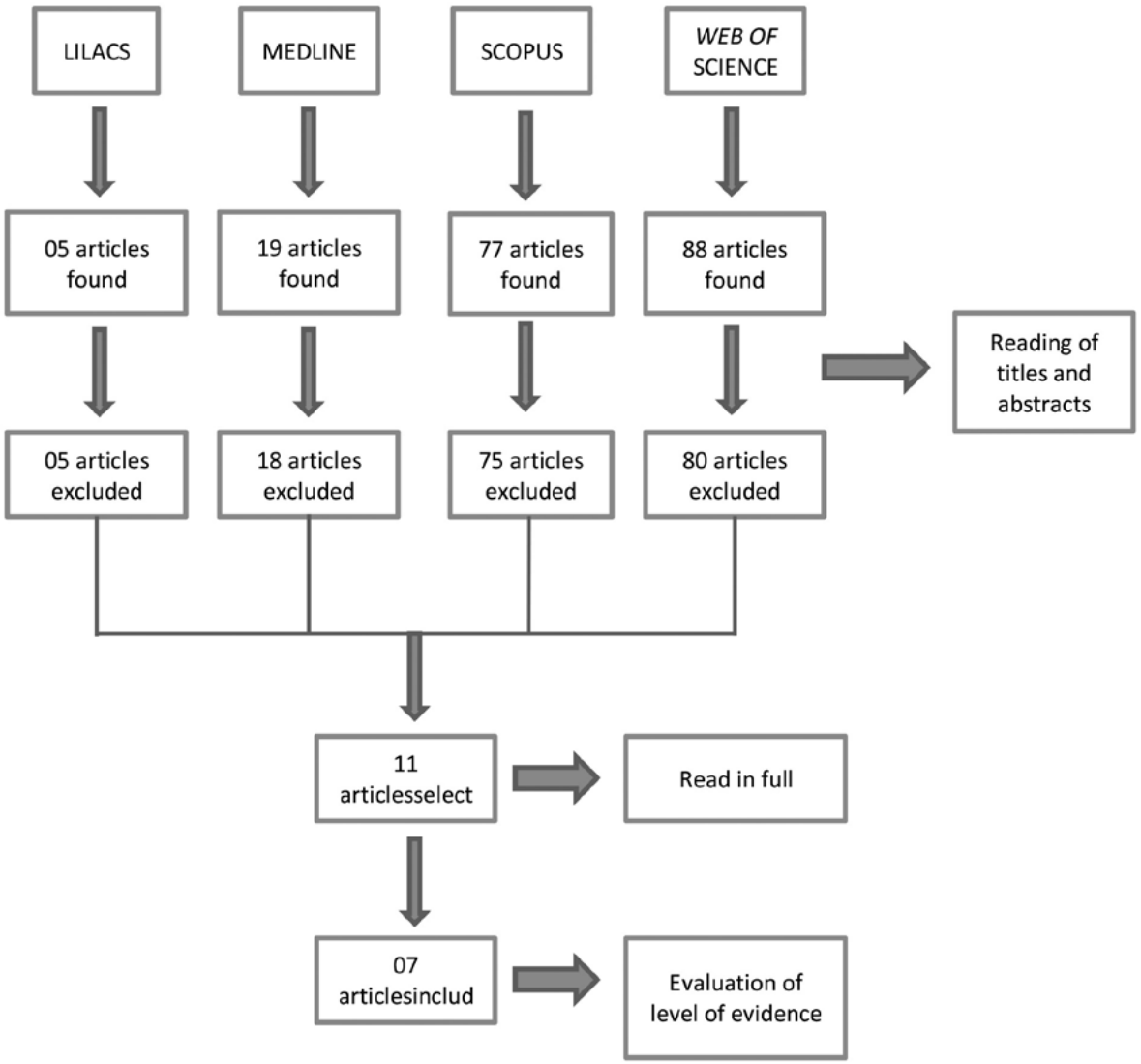

Figure 1. Diagram of articles found and selected from database search. Recife, Pernambuco, 2018.

Chart 1. Characteristics and presentation of synthesis of articles included in integrative review. Recife, Pernambuco, 2018.

Authors/Year/ Local	Sampling	Database	Objectives and delineation of study	Principal Results/Conclusion
Okuno et al., 2014[12]/Brazil	201: -128 men -73 women Mean: 56 years	*Web of Science*	To evaluate the quality of life of the elderly with HIV / AIDS and to correlate it with the sociodemographic, economic and clinical variables presented. Epidemiological/ Cross-sectional/ Analytical	One of the domains with the lowest HAT-Qol scores was: concern for confidentiality, where there was a strong correlation between age and the stigma associated with the disease, referring to the devaluation, discrimination and judgment of the way of life and behavior of the elderly individual requiring social, family and professional support.
Okonkwo et al., 2016[13]/ Ireland	45: -35 men -11 women	*Scopus*	To determine the level of perceived social support among elderly people living with HIV and AIDS in Dublin Quantitative/ Cross-sectional	A little over half of the elderly participants scored poorly in perception of social support. Social support in the form of emotional and informational assistance provided through the appropriate channels has been shown to improve people's quality of life. However, more can be done by formulating strategies to encourage older people to participate more proactively in the community to which they belong through voluntary services that keep them physically and mentally active and more intrinsically involved with the community.
Warren-Jeanpiere et al., 2017[14]/USA	23 women Mean: 57 years	*Web of Science*	To describe the perceptions of elderly African American women about aging and the chronicity of HIV and how this affects their social support needs Qualitative	In the analysis of the focus group, four central themes were perceived: "Life begins at 60", marking a positive change in the identity of the elderly, as they reached a point of acceptance in life, despite their HIV status. "Stop worrying about everyone else" shows the perception of the elderly is to desire the instrumental and emotional support that can facilitate self-empowerment and in turn improve the self-management of HIV. "Silence is killing us," indicates the need for emotional support of the elderly in order to resist the stigma of HIV. "I need something more," means that elderly women need ongoing emotional and instrumental support as they grow older with HIV.

to be continued

Continuation of Chart 1

Authors/Year/ Local	Sampling	Database	Objectives and delineation of study	Principal Results/Conclusion
Emlet et al.,2013[15]/USA	226 men Mean: 62.9 years	*Web of Science*	To analyze risk and protection factors associated with physical and mental health-related quality of life among gay and bisexual people living with HIV. Quantitative/ Cross-sectional	Social support and self-efficacy were positively correlated with quality of life related to physical health, where they are factors of protection for quality of life related to physical and also mental health, where a significant result was obtained.
Furlotte et al.,2017[16]/ Canada	11: -9 men - 11 women Mean: 60 years	*Web of Science*	To analyze how the elderly living with HIV describe their experiences in mental health Qualitative	Engagement with social support is one of the strategies for achieving resilience, based on an individual approach. The elderly noted that the social support sought and received (family, peer group, spiritual) positively affected their quality of life and this search for social support helped to promote resilience. The elderly value the support of psychological services, showing the importance of formal social support for the elderly with HIV.
Johnson et al.,2009[17]/USA	244: -173 men -71 women	*Medline*	Comparison of alternative models for adherence to antiretroviral drugs among the elderly living with HIV/ AIDS Randomized Clinical Trial	Relationship of direct effect of social support with maladaptive coping and adherence to antiretroviral therapy. The study emphasizes the importance of social support in influencing behaviors and results for health, as well as the importance of intervention in groups to improve coping with the disease and in the relief of psychological suffering.
Daskalopoulou et al.,2017[18]/ UK	3258	*Scopus*	Evaluates whether the non-disclosure of HIV status is associated with psychological symptoms, adherence to antiretroviral therapy and viral load among people living with HIV in the UK. Multi-centric Clinical Trial	The elderly had a higher prevalence of the non-disclosure of serological status in a social context, especially those with a long-term partner, when compared to other age groups and types of marital relationships. Elderly persons in a relationship were more likely to have low social support or to experience psychological symptoms.

The seven articles found were published between 2009 and 2017(based on the inclusion criteria of publication in the previous 10 years). Two were published in European countries (the UK and Ireland), three in the USA, one in Canada and one in Brazil. One article was evaluated as evidence level II and six scored level VI.

Most of the findings came from cross-sectional and descriptive studies, with the direct observation of a planned number of people with HIV/AIDS in a single moment, preventing the long-term comparisons of the characteristics of the sample.

DISCUSSION

Although few articles were found using the search key and eligibility criteria, some important points arose through the construction of this study, namely that great importance is attached to social support in the life of the elderly with HIV/AIDS, as well as the genuine need for such support and help.

The search for means of help or support is considered a natural reaction of human beings who are going through difficult situations under severe stress. In other words, there is a search for support networks, both formal and informal, aimed at coping with the changes generated after HIV diagnosis[19].

Many studies of elderly persons living with HIV/AIDS highlight the fact that this population is at risk of a deterioration in their psychological and physical health when such social support from friends and family is inadequate[12,17,20].

In a study of individuals aged 50 or more living withHIV/AIDS[21],it was found that such individuals are more likely to reside in nursing homes than those who do not have HIV/AIDS. The reasons that led to this difference in types of residence were the fact that those living with HIV/AIDS said that they were not able to rely on emotional and/or financial support from their relatives, with the implication that such a lack of support results in a decline in their physical and emotional health. The elderly tend to have a reduced network of social support and ways of dealing with psychological and social stressors, resulting in a perception of lower social support.

A greater propensity of elderly persons without parents and/or who may have an older partner with declining health may suffer limitations in both the type and level of support available to them[22]. In the study by Okonkwo, Larkan and Galligan (2016) it was found that slightly more than half of the elderly participants had a low perception of social support. In the analysis of this study, emotional and informational support was found to improve the quality of life of these elderly people living with HIV/ AIDS, when provided through the proper channels[13].

HIV-related stigma and prejudice have a number of negative consequences for the fight against AIDS, both for people living with HIV and for prevention strategies[6]. In addition, the reality of being old and living with HIV/AIDS is often shocking, unthinkable and difficult to accept, since it contradicts the stereotypes specifically related to the elderly, which are mainly related to conceptions of asexuality at this time of life[23].

One of the studies that used the HIV/AIDS Quality of Life test (HAT-Qol)[12] (a specific instrument for evaluating the quality of life of individuals living with HIV/AIDS) supported this idea of the negative impact of socially constructed stigma and prejudice, as one of the domains assessed most negatively by these elderly people was "concern with confidentiality", which may be related to the stigma connected with the disease, leading to the devaluation, discrimination and judgment of the way of life and behavior of these elderly people living with HIV/AIDS.

All such biopsychosocial impacts means the elderly require social, family and professional support, as the discovery of the diagnosis can generate changes in several aspects of the life of these individuals. In relation to disclosing the news of a positive HIV diagnosis, many prefer to live in silence, for a variety of reasons: lack of a social support network or insufficiency thereof, fear of stigma, abuse based on stereotyped views of people living with HIV, loss of social support, breach of confidentiality and the desire not to burden family members with problems of health[24].

In the study aimed at analyzing whether non-disclosure of HIV status is associated with psychological symptoms, non-adherence to antiretroviral therapy and viral load among people living with HIV in the UK, the elderly were more likely to have low levels of social support or experience psychological symptoms, in addition to having a higher prevalence of non-disclosure in a social context and lacking a long-term partner, compared to other age groups[18].

In addition, there is a possible association between HIV/AIDS in old age and a greater perception of the level of stigma among the elderly than among younger people. In a qualitative study[25] conducted with 63 African American, Latino and Caucasian elderly people with HIV, several barriers to social support were identified: age bias, family unavailability, non-disclosure of diagnosis, HIV stigma and concern about not becoming a burden. Despite these statements about the non-disclosure of HIV status, disclosure can also represent a strategy for providing social and psychological support to overcome a diagnosis which is in many ways more complex than other chronic conditions[26].

The elderly have formal and informal support needs. In the studies, informal support was the resource that is most received and perceived by the elderly (family, friends, neighbors and religious communities)[27,28].

However, one study shows that the elderly living with HIV/AIDS are more disconnected from informal sources of support, often leading to gaps in care, thus requiring support from health professionals, companies and formal integral care services[21].

In the study which sought to observe the social support needs of African-American women who were HIV-positive, the elderly individuals described a need for emotional support (talking to others, feeling close to others, pampering themselves), informational support (adverse effects of medication, family support group information, mental healthcare provider information) and instrumental support (transportation assistance, health insurance). One of the needs highlighted by the elderly women is the desire to talk about their HIV-related and general concerns about life with other people who would act empathetically and not be judged[14].

These elderly women described the need to express their concerns, thoughts and experiences about aging with HIV and seek advice from doctors, therapists, family members and friends living with HIV/AIDS[14]. These types of support which are described as necessary for the elderly should be provided continuously as these people age with the disease, making them a facilitator in building self-empowerment and the self-management of HIV[14].

The participants found the search for informal social support more useful although, due to the simultaneous occurrence of HIV stigma and the aging process, these elderly persons tend to find it more difficult to seek social support from informal sources to assist them with the condition, compared with other chronic diseases[14]. Again the stigma acts as a barrier in the search for social support, especially from informal sources. The study by Poindexter and Shippy reached a similar conclusion, with African-American women living with HIV aged 50 to 83 years revealing that they did not consider their families to be a reliable source of social support[29].

This importance of social support in the lives of elderly people with HIV/AIDS and their need for such help and support is further emphasized with other studies selected in the review, where social support and self-efficacy were considered as protection factors for quality of life. mental health and physical health, contributing to the "cushioning" of life's adverse events and contributing to better adaptability when faced with these changes[15].

Social support is a protective factor in promoting resilience in old age, since many elderly people living with HIV experience uncertainties and stigmas that may contribute to mental suffering, requiring consistent and structured social support to be able to use resilience as a coping ability and an important pillar in the lives of these elderly people. It was also found that the social, family, peer group and spiritual support sought and received positively affected the quality of life of these elderly people, as well as promoting resilience[16].

When inadequate, social support has been directly related to poor adaptive coping with the condition of HIV/AIDS. The negative affect of this social support completely mediated the associations between maladaptive coping and adherence to antiretroviral therapy, emphasizing the importance and necessity of social support in the influence of behaviors and results for health[17].It is likely that improving coping, support and affection will positively influence the adherence of the elderly to the management of the disease[30].

Limitations of the present study include gaps in detailed theoretical information and explanations of fundamental concepts such as social support and help in most of the studies, and also the fact that social support was evaluated in most of the studies in a secondary form. The research included in this review was carried out in several socio-cultural contexts, which may lead to different results, and few longitudinal studies were found, with the cross-sectional approach most prevalent among the studies analyzed in the review.

CONCLUSION

The present integrative review identified far fewer studies than might have been expected considering the period investigated, the significance of this epidemic in the elderly population, and the importance of both formal and informal social support in the life of these elderly persons. There is therefore a shortage of scientific production on social support for the elderly in the context of HIV/AIDS, especially in terms of the primary analysis of social support in scientific research.

Social support has been shown to play a role in contributing to the quality of life of the elderly living with HIV/AIDS, as well as having a negative effect when absent or inadequate, considering the burden of diagnosis and treatment and the stigma attached to the disease. Support becomes a strong ally throughout the process of dealing with the disease.

The elderly suffer a greater stigma in relation to HIV/AIDS than other age groups, and those living with HIV/AIDS among this population receive less social support, hindering care. Because of this stigma, many face the disease in a solitary manner, generating negative feelings throughout its course, thus reinforcing the need for informal social support from relatives, friends, as well as the formal support provided by professionals and reference services. This support can help to avoid negative consequences in terms of adherence to treatment, isolation and difficulties in seeking help when required.

Reactions to elderly persons with HIV from family members may be influenced by the meanings given to the disease by society, resulting in situations of discrimination and exclusion by the family group.

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Interaction between incarcerated adolescents and their grandparents in the processes of living and ageing

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Abstract

Objective: To describe the interactions between incarcerated adolescents and their grandparents during the processes of living and ageing. *Method*: An exploratory, descriptive, qualitative study was carried out, based on a semi-structured interview with 11 adolescents aged from 17 to 20 incarcerated in a youth detention center in the state of Rio Grande do Sul, Brazil. The discourse of the adolescents was analyzed based on content themes. *Results*: Categories that were both intertwined and complete among themselves were constructed: a) grandparents as affective support for incarcerated adolescents and b) relationships of reciprocity and healthy coexistence between the adolescents and their grandparents. *Conclusion*: The results showed that despite relational conflicts, the participants perceived the role of their grandparents in their lives as beneficial, as they offer a familial reference space, providing shelter and affection against the anxieties of the adolescents and those related to their families. This form of coexistence was a potential part of the development of young people in conflict with the law, and a favorable environment of mutual exchanges and learning, and as figures continuing the transgenerational family culture. Family separation was mentioned as a recurring and underreported process in the lives of adolescents and their grandparents.

Keywords: Grandparents. Adolescent. Family Relations. Aging.

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INTRODUCTION

Recent years have seen a number of changes in population demographics. The population has increased, the age structure has changed, and there has also been a relative increase in the number of elderly people. The phenomenon of ageing is connected to swift and complex political, economic and social changes, which often coincide with important changes in family life and family ties[1], meaning that a longer life results in a longer period of coexistence between grandparents and grandchildren.

The social and family changes that stem from the ageing process also bring profound changes to the roles of grandfather and grandmother, with teenagers often being brought up by their grandparents[2]. The reasons behind this new model of family life include teenage pregnancy, divorce, parents who live alone, incarcerated parents, drug abuse, child abuse, domestic violence[3], difficulty in establishing bonds with one or both parents, situations at work, parents who are emotionally immature[4]. In such circumstances, grandparents must take on parental responsibilities towards their grandchildren, and sometimes must be fully responsible for their care. However, responsibilities extend well beyond daily care, with grandparents also responsible for financial commitments and obtaining legal custody of the grandchildren[5].

A survey of children and adolescents with incarcerated family members, in the Brazilian states of São Paulo and Amazonas, and in the Federal District of the country, found that these young people report being in their mother's care, when their father was incarcerated, or under the care of their grandparents, with aunts/uncles and other family members the third and fourth choices[6].

A systematic review of literature regarding guardian grandparents[7] reveals that children brought up by grandparents are considered to high risk, with a strong likelihood of problems at school and not being successful in life, due to the probable traumatic events that caused this family configuration.

This means that, in most cases, adolescents in conflict with the law find themselves in situations of social vulnerability. According to the National Justice Council (or CNJ), some 22,640 young people are currently incarcerated in Brazil, in one of the 461 youth detention centers that exist in Brazil, having committed an infringement of the Law. Of these, 3,921 are provisional inmates, who do not yet have a definite sentence[8].

Fonseca et al.[9] show that children and teenagers are vulnerable to environmental and social situations, which often involve routine violence within the family and the school environment, forcing children into work and/or drug trafficking. This situation suggests the absence and/or insufficiency of social apparatus, and the repercussions thereof result in increased opportunities for involvement with crime[10].

The Brazilian Statute of the Child and the Adolescent (or ECA) states that the required age for possible admittance to youth detention centers is between 12 complete years and 20 incomplete years, and that this measure should be seen as a last resort following a series of other possible social and educational measures[11]. The ECA adds that this incarceration shall take the form of the deprivation of freedom subject to the principles of brevity, exceptionality, and respect for the specific characteristics of the developing individual. The statute therefore addresses the issue of incarcerating the young person, when the infringement of the law involves serious threat or violence against the person; the repeated commission of other serious violations of the law, and/or by repeated and unjustified failure to comply with a previously enforced measure[11]. In the Brazilian State of Rio Grande do Sul, the state organization responsible for the incarceration of youth offenders is the Socioeducational Service Foundation, (*Fundação de Atendimento Socioeducativo* or FASE), which consists of several regionalized youth detention centers known as *Centros de Atendimento Socioeducativo* (or CASE).

Investment in studies on the life trajectory of adolescents in conflict with the law, and also their affective family ties, representativity and identification with older parental figures helps us to understand the situation in which grandparents establish the concepts of life they have constructed.

Research has also shown that, while grandparents help their grandchildren, they also take care of them

as a result of their parents absence through work, offering financial support and monitoring their daily routines[12]. This type of coexistence between different generations, involving affective care, brings benefits to both sides.

The relationship between grandparents and grandchildren, which has the effect of a bond of caring, and includes both emotional support and the provision of resources, is known as grandparenthood. Grandparenthood, which translates into an exchange between grandparents and grandchildren, is a fairly recent phenomenon, resulting from increased life spans and characterized by the execution of decision-making roles based on a dual condition of mother/father-grandmothers/grandfathers, in an intergenerational transmission process, and is related to the development of the subject, namely the grandchild[13].

The transmission of principles, the sharing of life stories and even of habits and culinary recipes, represents a type of exchange of experiences, so that the older person feels more valued[14]. In addition, solidarity between generations, namely between the elderly and the young, can also help to resolve individualism in relationships, which arises from the tensions of coexistence to which we are accustomed[15]. The study also shows that taking care of grandchildren, the children of parents who have separated, passed away or simply no longer wish to take responsibility for rearing their offspring, allows the grandparents to experience satisfaction, well-being, love and happiness[2]. Because of this coexistence between different and often distant generations, the study of the conceptions of incarcerated adolescents regarding their relationships established with their grandparents throughout their lives is highly significant.

Within this scenario, the main goal of the present study was to understand the interaction between incarcerated adolescents and their grandparents, as part of the process of living and ageing.

METHOD

This is an exploratory, descriptive and qualitative research study, using a qualitative approach, developed in a CASE unit in the state of Rio Grande do Sul, where there were 68 adolescents who had infringed the law. A total of 11 incarcerated adolescents, aged between 17 and 20, took part in the study. The following inclusion criteria were established: adolescents with a final sentence defined by the Brazilian Juvenile Court, who had been definitively sentenced to incarceration and who had lived with their grandparents at some point in their lives. Temporarily incarcerated adolescents were excluded, as they could leave the system at any time. The definition of the sample also used the criterion of theoretical saturation, as proposed by Fontanella et al.[16].

In-depth interviews were employed, as these are considered useful in qualitative research, as they assume the possibility of the transmission of issues involving subjectivity as contained in the coexistence of the subjects, and also their singularities[17].

The data was collected through individualized interviews by a single interviewer, in February and March 2018. The study used a social and demographic questionnaire to characterize the participants, and also guiding questions to meet the aims of the survey, including the type of offence committed, whether drugs were used, the type of coexistence with parents and grandparents, the importance of these people in their lives, and what they think of ageing and its meaning. The interviews took place on the CASE premises, in a suitable room, to preserve the confidentiality of those involved. Absolute secrecy was applied to the data obtained and with the permission of the people involved, the interviews were recorded and transcribed in full, for subsequent encoding and analysis, with the guarantee that this information would be destroyed at the end of the survey.

The participation of the adolescents in the study was entirely voluntary, and was formalized through the signing of a Free and Informed Consent Form.

The responses of the adolescents underwent content analysis[18] carried out by a panel of three evaluators, one of whom was the interviewer and two of whom were well versed in the fundamentals of intergenerational relationships and also experienced in content analysis, especially the skills of categorizing,

comparison, and seeking agreements among systems of themes and categories. Content analysis consisted of three phases: the first phase, namely pre-analysis, consisted of the construction of the corpus through a skim reading of all the responses, seeking to identify meaning units (verbal utterances of any size involving statements about the relationships of the adolescents with their grandparents). The second phase involved division into categories under the supervision of the experts. Finally, in the third phase there was a general review of this separation into categories, and the final treatment of results, inference and interpretation[18]. The participants were all identified by the letter A (for adolescent) followed by a number, according to the order of the interviews, to ensure the total anonymity of those involved. This research study was approved by the Research Ethics Committee of the Universidade de Passo Fundo, under opinion statement No. 2.408.199.

RESULTS AND DISCUSSION

The ages of those involved ranged from 17 to 20. For most of these adolescents, entry into FASE occurred at the age of 16 years old, while five of the 11 adolescents interviewed were repeat offenders. The crimes committed by these incarcerated adolescents were: theft, drug trafficking, and crimes against the life of others, including murder and first-degree murder. With regard to criminal activities in their families, eight of the adolescents reported that they had family members had also had problems with the law. Out of the 11 adolescents interviewed, five knew only their mothers, as either their fathers had died or the couple had separated. The self-reported family income was between one and two Brazilian Minimum Wages (MW), for most of the households of the adolescents; in the others, the family income was less than one MW.

The discourse of the adolescents was then subjected to content analysis, and was then divided into categories that overlapped yet completed each other: a) grandparents as affective support for incarcerated adolescents, and b) relationships of reciprocity and healthy coexistence between adolescents and their grandparents.

Grandparents as affective support for incarcerated adolescents

Based on the reports, it can be seen that the grandparents are figures who are present in the family unit, and also that grandparenthood[19] occupies a prominent position within the family, sometimes even taking greater importance than the image of the parents.

In contrast, this information shows, in some cases, a gender gap in relationships established throughout life, with women, be they mothers or grandmothers, playing a visible role:

> "I lived with my grandmother, who brought me up, for a long time. It was a very good experience. [...] They (the grandparents) treated me as if I was their son [...]. She (the grandmother) does not want me following that other path, using drugs and living on pavements like a beggar" (A2).

> "I lived alone with my mother. However, my grandmother would always go there to give me guidance [...] My mother would speak to me, buy it would go in one ear and out through the other. I wouldn't listen to her. My grandmother would also come and talk to me. I didn't listen to either of them" (A11).

The statements of A2 and A11 showed the influence that these grandmothers have on adolescents, results consistent with specialized Brazilian and international literature, which shows the maternal prevalence in relationships with grandparents[1,3,10,20]. According to A2, this substitution exceeds practical and instrumental limits, being inserted in the imagination of the grandchild, and representing an important reference for the grandchild, reported in the mention of the consideration the grandmother has for the child. In the opinion of A11, the advice given by the grandmother is still remembered to this day.

Considering these statements, it can be understand that, possibly, the echo reverberates as a result of the fact that intergenerational relations can also be marked by differences and conflicts, a healthy form of coexistence, as shown in a study carried out

with adolescents aged between 15 and 18 years old, in which benefits were found, as differences and conflicts are important for setting limits on behavior and the operating customs of the family unit[21].

Regarding their conditions of incarceration, the adolescents accept the attempts that the grandmothers have made to restrain their conduct, which is a subliminal way of enforcing limits and values[20], and is a long-standing aspiration of grandmothers, which in the past proved to be ineffective, as described in the perception of the grandchildren. The paradox of this type of coexistence between adults and adolescents is a change that is necessary in order to adjust their relationships[22].

It was also mentioned that there are many specific differences in the method and type of coexistence between generations, these being characteristic of the level of maturity and experiences of different lives, together with stereotypes produced by society and then reproduced by the adolescents:

> "With my grandmother, sometimes she has a turn. You know, she is getting on a bit" (A2).

> "They are a bit stubborn, and a bit hard to handle, you know?" (A11).

> "Older men, they just want to give orders, because they are not as flexible as someone younger" (A10).

The statements made by the adolescents show prejudice in relationships that are also full of negative connotations, reflecting the stigma with regard to elderly people that is present in society and in many families. This result is backed up by studies that confirm the negative view of grandparents within intergenerational coexistence, which is also impregnated with stereotypes that are firmly ingrained in the collective memory[23]. Torres et al.[24] commented that this is a cultural process where people apply prejudice within intergenerational coexistence, as this is how they see the world. Along similar lines, the research study made by Calderón[25], with incarcerated adolescents, showed that studies focusing on intersubjectivity are essential for the understanding of the individual and social dimensions of adolescents in conflict with the law.

Relations of coexistence are established within the family unit. Like parents, grandparents also have an educational role in their relationship with the grandchildren. With regard to this influence, adolescent A4, aged 20, mentions the educational character and general assistance provided by parents and grandparents:

> "My mother, my father, the people who have helped me most, my grandmother too [...] With my grandmother and my late grandfather, it was a good experience [...]. I learnt a lot through my grandfather and, had I listened to most of the things he said, maybe I wouldn't be here" (A4)

With regard to the educational process and the coexistence between grandparents and teenagers, the statement of A4 shows that family relationships have been based on an interaction between parents, grandchildren, and grandparents, marked by beneficial influence[19,20] and affective ties that add value to life experiences in different generations[23].

Several changes have occurred within the makeup of the families. Often, grandparents are responsible for caring for their grandchildren[2,26]. However, the statement made by a participant shows conflicting family relationships:

> "So, I started to curse at my grandmother, you know? Then she got very cross with me, and then I went to live with my mother [...]. Later I went back to live with my grandmother, and she did not like me trafficking drugs or robbing [...]. So, I lived with my aunt for a while [...] and then went back to live with my grandmother" (A2).

The statement made by A2 shows a situation of conflict amid disharmonious relations, which suggests an incompatibility of social and cultural values between the adolescent grandson, a thief and drug dealer, and his grandparents. A lack of flexibility on the part of the adolescent in the light of the statements made by his grandparents can be observed. The only choice was to flee, to move house, maybe at the insistence of his grandparents in discussing his living and coexisting with criminal offences.

Relations of reciprocity and healthy coexistence between adolescents and grandparents

The narratives reinforce the link with, and attachment to, the family, praising the affective involvement and ties between adolescents and their loved ones who despite the difficulties, are always loved and included in future expectations. One of the participants describes the meaning of the affective ties with loved ones, which also represent a reference when trying to change behavior and the pleasure of occasional coexistence:

> "My godmother came to see me, and when I looked at her I wept, as I had not seen her for six months. My grandmother is very important: everyone is important for me, as they are, sort of, part of my life […] My grandmother is already elderly, and I am very much afraid that something will happen to her, a true fact, something like that, so the people who are important to me are like my treasures, my sources of energy, you know? Like God, Jesus, things like that […] And I feel very happy, you know? […] I go there every Saturday, so I spent and spend time with elderly people like that […] and I intend to spend time with my grandmother for a long time yet" (A11).

Relationships between different age brackets of the population produce ties based on affection, care and the social and psychological life between those involved. In the statement made by A11, the feelings with regard to his grandmother take on proportions wider in scope, where positive feelings are prevalent. Apart from harmonious relationships, the possibility of losing a loved one brings fear and worry, as there is quality in this relationship, as well as emotional involvement and a family structure that is closely linked to well-being throughout life[27].

With regard to reciprocity within a positive family environment, the statement made by A9, aged 18, who has been incarcerated as a result of robbery, reveals his perception of trust, friendship, hope, and psychological support with regard to family members:

> "I consider that the people who are most important to me are my mother, my late brother, my grandfather and my friend D. My grandfather is really great […], I came over on a family visit and at home he started to cry, he cried in front of me, and said he did not want me here anymore, and asked me to change. I am afraid of losing my grandfather, and be in here [...] I always take grandpa's chair, I go there and put the chair in its place, Grandpa sits there and I leave him alone, or stay there talking to him, but at six o'clock in the morning I need to make him some mate tea." (A9).

The literature[10,13,23] confirms this reciprocity as perceived, in some cases, in the relationships between grandparents and the grandchildren they care for, highlighting the importance of the reproduction of the family culture between different generations, thus upholding a healthy and active process of ageing of the grandparents.

Within a family context, there is a constant exchange between the different psychological realities of each family member. The essential roles are constantly alternating and being reconstructed. The method of healthy coexistence with other people means that bad habits must be constantly overcome, and new habits are being acquired and legitimated.

> "I went away to live with them (my grandparents), and then I briefly stopped having a wildlife, living just to party and things [...] And then I went to live with them, and they exercised more control over me [...]. Then I started to go back to study and work, and then I started working again, with my grandfather. My grandfather was a construction foreman [...] So all my family, they all gave me a lot of support in here […] I have great affinity for my great-grandmother as well, and also get on well with my grandparents" (A8).

The destructuring of the family is a recurrent process subjacent to the lives of teenagers, and the grandparents appear as a kind of reference, to ease this instability, be it positive or negative, as they are physically present and also have life experience, including experience in groups. This kind of coexistence is also an option within the search for quality in forming the personalities of young people in conflict with the law, and an environment which encourages mutual support and exchanges.

> "[...] He (referring to his grandfather) taught me tons of things. He taught me... And I felt calmer when I was with him. When I was with him, I was calmer, and did not think about the streets so much" (A10).

> "I mean, I used to spend time with my grandmother, I mean I still spend time with her, yeah? She very old, and she sees me, you know? And this makes me very happy, you know? Because, you know, she comes over every Saturday, "*even if I take the bus, I go there every Saturday*", so I did and do spend time with her, she is very important to me" (A12)

In confirmation, a study carried out in the Federal District, appraising the relationship between grandparents and grandchildren according to their perceptions, found, in the category of feelings, a result showing that the grandchildren tend to bring out the personal qualities of their grandparents, constructing different types of relations between them. In the 'significance of advanced age' category, some of the grandchildren showed that they were unaware of what the term meant, while other people did indeed have some idea of what advanced age would be, in their minds[28].

According to Almeida[27], when there is intergenerational contact, affective exchanges are then established. In daily life, the subjectivity of the child or the adolescent is created and reveals itself, through interaction between one's own self and the important people within the family unit, be they grandparents, father, mother, and siblings.

In this context, a study carried out with 30 elderly people who took part in a further study product at the University of Maturity at the Universidade Federal do Tocantins, 70% of whom have legal and financial custody of their grandchildren, showed, in declarations made by the participants, that having an extended role has a positive effect, through a feeling of personal renewal and that one has done one's duty, but may also have a negative effect, through possible conflicts and financial burden[29].

The statement by A8 shows the moments of emotional approximation and interaction between grandparents and grandchild, and here we see a feeling of transmission of certain family values, and of strengthened generational bonds. It is quite likely that the "control" as exercised by the grandparents was echoed in the conduct of the teenager, as the style of exercising grandparenthood caused changes in the behavior of the grandchild. Thus, grandparents have an important role to play in the transmission of family values to adolescents[5,30], in the new family configurations. The experiences of A8 demonstrate a possibility that extends well beyond the support given to the grandchildren by the grandparents. These are affective ties that have been established and have become stronger, overcoming situational and socioeconomic difficulties and also important components for a condition of living which is detached from social or individual vulnerabilities. Stronger interpersonal ties, in the intergenerational dimension, make a positive contribution towards the process through which the adolescents live and age. The operation of the family context, during life, reflects the ability that individual people have, to adapt to challenges and limitations of the social environment and also the events of the life cycle[28,31].

Limitations of the present study include the fact that it involved a small group of adolescents of very similar realities, which means that generalization is not possible. Further studies in other sociocultural and economic contexts would be of value.

CONCLUSION

The results of the present study show that the participants consider the roles of the grandparents in their lives as beneficial and healthy, even with relational conflicts. They occupy a space of family reference and coexistence that has not been filled by the parents, providing care, affection and support in situations of family distress and problems characteristic of adolescence, contributing to the construction of the personal identity of the adolescent. Elderly people are also mentioned as being bearers of the transgenerational family culture among family members, thereby generating some homoeostasis in relationships within the family.

It is also important to stress the key role played by women who, within the overall scenario in which there

is a need to assume custody of their grandchildren, can also find themselves in a situation of vulnerability through their own impairment, especially with regard to their physical and emotional health.

The dialogue with participants showed the results of the ageing process and of increased lifespan, as the number of families with the presence of elderly people is steadily growing significantly, especially with regard to the universe of intersubjective relationships as established between young people and the elderly. From this standpoint, it is useful to understand these familial and intergenerational relationship dynamics within their own contexts and specificities, especially through more profound studies involving a greater number of subjects.

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Analysis of the cognitive aspects of elderly people considering the practice of regular physical exercises and associated factors

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Abstract

Objective: The objective of this study was to compare the cognitive performance of elderly who are enrolled in a physical activity (PA) program with those who are not, considering some sociodemographic variables that are related to the practice of cognitive activities. *Method*: 59 elderly people participated in this study divided into control group (CG) and gymnastics group (GG). The Vienna Test System® was used to estimate the attention and concentration capacities, simple reaction time and peripheral perception. To test the normality of the data it was used the Shapiro Wilk Test. The association between PA and socioeconomic variables was verified by Chi-Square Test and Fisher Exact Test. To compare of differences between groups the Mann Whitney U-test for variables with non-parametric distribution and the Student T-test for independent samples for other variables were used. *Result*: There were no significant differences in the performance of the groups, except in the capacity of attention and concentration in which CG presented best performance (p=0.01). Factors as schooling (p=0.02), income (p=0.001) and regular practice of handcrafts (p=0.06) can explain the best performance of CG. *Conclusion*: This study found no evidence that the practice of physical activity can generate some cognitive benefit in the elderly when compared to the elderly who did not practice regular physical activity. However, we perceive the existence of other aspects that influence on the cognition, such as schooling, sociocultural level and the reading habit, that have a significant importance degree in the analysis.

Keywords: Aging. Reaction Time. Attention. Psychomotor Performance. Visual Acuity.

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INTRODUCTION

Senescence brings with it cognitive limitations resulting from changes in the central nervous system, reduced nerve conduction and sensory perception that interfere with executive function and psychomotor performance[1,2]. The search for evidence that optimizes the use of non-pharmacological strategies in an attempt to mitigate these alterations has gradually increased[3,4]. Evidence suggests that a high level of regular physical activity is associated with better physical, motor and cognitive performance, reducing the risk of cognitive decline and dementia in adulthood[5]. However, the mechanisms of relationship between physical exercise and cognitive functioning in the elderly are still not well understood[6].

Cognitive processes such as focused attention, reaction time, and peripheral perception are extremely important for the day to day life of the elderly. They are directly related to the ability to focus attention on the relevant stimuli of the environment[7] as well as respond quickly to environmental stimuli[1] and perceive the environment around them through spatial orientation in order to avoid possible accidents and perform daily activities with effectiveness[8]. Therefore, further clarification on the importance of physical activity in cognitive aspects becomes important in order to elucidate possible intervention strategies against the cognitive decline of older people.

According to the conclusions of Bherer, Erickson, Ambrose[2], physical activity is a promising non-pharmaceutical intervention to prevent cognitive decline related to age and neurodegenerative diseases, mainly due to the improvement of cardiorespiratory capacity. Freudenberger et al.[9] also add that better cardiorespiratory fitness is highly related to better performance in the cognitive domains of memory, executive function and motor skills in middle-aged and elderly individuals. However, a recent literature review[10] did not find significant evidence between aerobic physical activity and cognitive function improvement in the elderly without known cognitive impairment. These findings corroborate Desjardins-Crépeau et al.[11] who also argue that not all executive/mental functions are improved with physical activity. For a better understanding of the relation of physical activity to cognitive conditions this study was structured, which compared the cognitive performance of practicing and non-regular physical activities adults, considering some sociodemographic variables and related to the practice of cognitive activities.

METHOD

For the formation of the active elderly group, gymnastic practitioners (GG) from groups linked to the Integrated Nucleus of Studies and Support to the Third Age (INSSTA) of the Universidade Federal de Santa Maria (UFSM) were invited to participate in the research. In order to minimize the possible performance differences caused by different stimuli, only groups that practiced classes with the same teacher were selected. Thus, a total of 200 elderly people practicing three INSSTA gymnastics groups were invited to participate in the study. The gym classes were held twice a week, lasting 50 minutes. Normally, classes were subdivided into warming up (dancing in pairs) and stretching; main part with choreographed dances, coordinating exercises for upper and lower limbs and / or functional circuits; finally, the overall stretching in groups or individual. The level of physical effort during class was not measured.

For the formation of the elderly group, those who did not practice physical activity, called control group (CG) were invited to participate in the research, elderly people living in the same neighborhoods of the active elderly, indicated by the GG participants. There was also a publicizing in the media through publication in newspapers and digital media.

A group of 63 elderly people was interviewed in the gymnastic group; from this group, 17 individuals were excluded because they did not reach the minimum score in the MMSE, eight individuals due to uncorrected auditory or visual problems, four individuals had a greater percentage of absences than allowed, four individuals practiced another PA and one person could not complete the battery of tests due to difficulties in manipulating the computer. In the control group, 50 elderly people were evaluated, among them eight were excluded in the MMSE,

seven were classified as active in the IPAQ and five presented uncorrected auditory or visual problems.

Thus, after interview, and according to the criteria of inclusion and exclusion of the study, the GG group was composed of 29 elderly people with a mean age of 69.43 (±4.63) years. In CG, the group had 30 participants, with a mean age of 69.93 (±5.05) years. It is understood that chronological age influences cognition in general, so the groups were classified into age groups, arranged in Gymnastic group 1 (GG1, n=17, for participants aged 60-69 years) and Gymnastic group 2 (GG2, n=12, for participants aged 70 to 79 years). The same division by age group was done with the Control Group by dividing it into Control Group 1 (GC1, n=15) and Control Group 2 (GC2, n=15).

For the formation of the GG, elderly people aged between 60 and 79 years of both sexes, effective participants of the gym classes in the groups referred for at least six months were invited to participate in the research. In addition, the practice frequency of the exercise was established as twice a week, with a minimum frequency of 75% of classes in the evaluation semester. For the CG, elderly people of the same age group were invited to participate in the study, who declared that they did not practice any regular physical activity for at least six months classified as insufficiently active or sedentary according to the International Questionnaire of Physical Activity (IPAQ)[12], according to classification of WHO[13].

Participants with physical and / or cognitive impairment, who could alter the study's evaluation variables were excluded, they were verified through an interview and by the Mini Mental State Examination[14], adapted to the Brazilian population by Brucki et al.[15], according to schooling. As well as visual sensorial deficit diagnosed through the Snellen Sign Scale, according to the Ministry of Health's indication[16]. In order to track possible auditory sensorial deficits, the whisper test[17] was applied, and participants were asked if they had serious hearing problems and / or hearing difficulty. People who declared that they had other physical activity, had diseases with decreased vision or had previous history of stroke, Parkinson's disease and Alzheimer's were also excluded.

Socioeconomic situation, health conditions, history of falls and cognitive stimulation were evaluated by means of a questionnaire, duly constructed for this research, in the form of an interview.

The Vienna Test System® software (VTS), Version 6.81.013 was used to estimate attention and concentration (COG), simple reaction time (SRT) and peripheral perception (PP). The tests used had an animated instruction phase and a training phase with error feedback, allowing the examinee to familiarize himself/herself with the test and ensure an understanding of the task. The two evaluators who carried out the research first went through a training process, a pilot project, in which 12 INSSTA practitioners of water aerobics were evaluated in two different moments. No significant differences were found between the results of the researchers.

In order to measure the cognitive profile of the participants, the Cognition Test (COG) version S7[18] was used. The test evaluates the general skills of cognition and is used to measure attention levels and concentration by comparing figures relatively to their similarity. The task of the examinee was to compare an isolated figure with a model block, and to evaluate its similarity. For equal figures the evaluated should press the green key, and for different figures should press the red key as fast and correct as possible. A total of 100 figures were presented, 50 being equal and 50 different to the model block. As a result, the number of correct rejections and the mean time (in seconds) taken to answer the comparisons were taken.

The analysis of the capacity of the simple reaction time (SRT) happened through the RT Test version S1, for SRT with visual stimulus, and RT Test version S2, for SRT with auditory stimulus[19].

The analysis of the simple reaction time (SRT) happened through version S1 (with visual stimuli) and version S2 (with auditory stimuli). The task was to hold the index finger of the hand preferably under a rest key and, whenever the stimulus, yellow circle or high-pitched tone is displayed, press a preset key as fast as possible. 28 stimuli were presented in each version of the test. For evaluation, the pre-motor and motor reaction time, given in milliseconds, were used.

In order to measure peripheral vision, the Peripheral Perception Test (PP)[20] was used. The PP consists of two partial tasks: the task of perceiving lateral stimuli pertaining to peripheral perception itself, and a central tracking task aimed at focusing the attention of the examinee to the center of the visual field and investigating the ability of the evaluated to distribute his/her attention. The examiner was asked to step on the pedal with his/her right foot whenever he/she recognized light stimuli on the right or left side of the panel but keeping a target close to a ball that moved on the monitor screen. 80 stimuli were presented, 40 on the left side and 40 on the right side, admitting a maximum field of view of 180°. As a result, the total visual field, in degrees, and the tracking drift in unmeasured unit were used. The image below (figure 1) illustrates the STV.

The image represents the cognitive, reaction time and peripheral perception tests, from the left to the right respectively.

Figure 1. Presentation of applied tests of the Vienna Test System®. Santa Maria, Rio Grande do Sul, 2016-2017.

Descriptive statistics were applied to the variables mean, median, standard deviation and interquartile difference. To test the normality of the results, the Shapiro Wilk Test was used. In order to verify the association between physical exercise and socioeconomic variables, health conditions, history of falls and cognitive stimulation, a measure of statistical significance was used for categorical variables. The chi-square test was used for the variables falls and manual work, of the groups between 60 and 69 years. Also, for the variables: marital status, income and comorbidities of the groups with ages between 70 and 79 years. For the others, the Fisher exact test was used. In the comparison of the differences between groups, the Mann Whitney U test was used for variables with non-parametric distribution (in the elderly group between 60 and 79 years old - Pre-motor reaction time for visual stimulus and tracking deviation). And, in the elderly group, aged 70 to 79 years, pre-motor reaction time, for auditory stimulus, motor reaction time, for auditory stimuli and tracking deviation. In the other variables, which presented parametric distribution, the Student's T-test was used for independent samples. All analyzes were performed using SPSS software version 20.0 for Windows, adopting a significance level of 5%.

This study presents, as ethical guidance, the requirements of Resolution 466/12 of the National Health Council, which regulates research involving human beings. The research began after approval of the Research Ethics Committee of UFSM and signing of the Term of Free Consent by the participants with opinion of approval nº1.154.499).

RESULTS

The socioeconomic characteristics, health conditions, history of falls and cognitive stimulation of the studied groups, stratified by age, are presented in Table 1. The variables schooling, family income and regular practice of manual work are highlighted with prevalence in the CG.

The IPAQ questionnaire was used to classify the level of physical activity of the elderly evaluated. A summation of the usual one-week physical activity practice time was made in the four domains of

the instrument. All the elderly individuals of the gymnastic groups were classified as active / very active. In CG1, three people were classified as sedentary, and in CG2 two people were classified as being sedentary, the rest of the participants in the control groups were classified as poorly active.

Table 1. Socioeconomic information, health conditions, history of falls and cognitive stimulation through absolute and relative frequency of the elderly (n=59). Santa Maria, Rio Grande do Sul, 2016-2017.

Variables	G1[1] (n=17)	C1[2] (n=15)	*p**	G2[3] (n=12)	C2[4] (n=15)	*p**
Age (years)	66.159 (±2.263)	65.666 (± 3.000)	0.806[a]	74.066 (±2.686)	74.194 (±2.219)	0.893[a]
Sex						
Female	16 (94.118)	11 (73.334)	0.161[a]	4 (33.333)	14 (93.333)	0.002[a]
Male	1 (5.882)	4 (26.666)		8 (66.667)	1 (6.667)	
Marital status						
Withpartner	4 (23.530)	7 (46.667)	0.266[a]	6 (50.000)	6 (40.000)	0.603[b]
Withoutpartner	13 (76.470)	8 (53.333)		6 (50.000)	9 (60.000)	
Schooling						
Up to 11 years of formal schooling	13 (76.470)	7 (46.667)	0.144[a]	12 (100.000)	9 (60.000)	0.020[a]
12 years or more of formal schooling	4 (23.530)	8 (53.333)		0 (0.000)	6 (40.000)	
Occupation						
Works	4 (23.530)	7 (46.667)	0.266[a]	0 (0.000)	2 (13.333)	0.487[a]
Doesn't work	13 (76.470)	8 (53.333)		12 (100.000)	13 (86.667)	
Family income (salaries)						
Up to 3	11 (64.706)	1 (6.667)	0.001[a]	5 (41.667)	7 (46.667)	0.795[b]
More than 3	6 (35.294)	14 (93.333)		7 (58.333)	8 (53.333)	
Comorbidity						
Up to 3 diseases	14 (82.353)	9 (60.000)	0.243[a]	7 (58.333)	7 (46.667)	0.547[b]
More than 3 disease	3 (17.647)	6 (40.000)		5 (41.667)	8 (53.333)	
Use of medicines						
Yes	13 (76.470)	14 (93.333)	0.338[a]	9 (75.000)	14 (93.333)	0.294[a]
No	4 (23.530)	1 (6.767)		3 (25.000)	1 (6.667)	
Falls						
Yes	6 (35.294)	5 (33.333)	0.907[b]	1 (8.333)	3 (20.000)	0.605[a]
No	11 (64.706)	10 (66.667)		11 (91.667)	12 (80.000)	
Handcrafts						
Yes	10 (58.824)	8 (53.333)	0.755[b]	4 (33.333)	11 (73.33)	0.057[a]
No	7 (41.176)	7 (46.667)		8 (66.667)	4 (26.666)	
Reading habit						
Yes	9 (52.941)	12 (80.000)	0.147[a]	4 (33.333)	11 (73.33)	1.00[a]
No	8 (47.058)	3 (20.000)		8 (66.667)	4 (26.666)	

[1]Gymnastics Group 1 (from 60 to 69 years); [2]Gymnastics Group 2 (from 70 to 79 years); [3]Control Group 1 (from 60 to 69 years); [4]Control Group 2 (from 70 to 79 years); [a]Fisher Test; [b]Chi-Square test.

In a second analysis we present the results obtained through the evaluation of cognitive and perceptive motor performance in the attention and concentration dimensions, simple reaction time (pre-motor) and motor time, for auditory and visual stimuli, peripheral perception and distributed attention capacity. The same distribution of groups was maintained. Table 2 shows the results of the tests and the comparison between GG and CG, which had similar performances, except for the number of hits, in the attention test, in which CG performed better (p=0.01).

Table 2. Cognitive and perceptive motor performance of elderly in Santa Maria, Rio Grande do Sul, Brazil, 2016-2017.

Variables	Age Group (years)	Gymnastics		Control		p
		Mean (dp[1])	Median (IQ[2])	Mean (dp)	Median (IQ)	
Atttention (nº of hits)	60-69	43.71 (3.31)	44.00 (5.00)	44.60 (4.55)	46.00 (6.00)	0.53
	70-79	44.00 (4.61)	45.00 (8.25)	41.53 (4.67)	42.00 (7.00)	0.18
Atttention (second stores pond)	60-69	1.98 (0.38)	1.98 (0.51)	1.62 (0.36)	1.57 (0.56)	0.01
	70-79	2.09 (0.45)	1.95 (0.53)	2.01 (0.39)	2.00 (0.62)	0.94
Pre-motor reaction time for EV[3] (ms)	60-69[#]	329.00 (72.32)	333.00 (61.50)	328.50 (81.96)	314.00 (36.00)	0.43
	70-79	328.20 (98.73)	295.00 (133.00)	329.40 (49.11)	321.00 (57.00)	0.97
Motor reaction time for EV[3] (ms)	60-69	305.40 (75.61)	301.00 (146.00)	308.10 (97.50)	319.00 (144.00)	0.93
	70-79	382.30 (118.00)	372.50 (112.50)	354.10 (73.12)	333.00 (119.00)	0.45
Pre-motor reaction time for EA[4] (ms)	60-69	245.90 (34.98)	240.00 (46.50)	264.70 (54.06)	255.00 (73.00)	0.25
	70-79[#]	316.90 (148.00)	247.50 (183.50)	284.40 (65.49)	292.00 (121.00)	0.94
Motor reaction time for EA[4] (ms)	60-69	259.80 (72.52)	275.00 (122.00)	282.50 (88.37)	289.00 (141.00)	0.43
	70-79[#]	327.60 (112.90)	315.00 (152.50)	310.80 (121.42)	273.01 (119.00)	0.71
Field of view (degrees)	60-69	132.30 (15.58)	133.90 (27.30)	136.80 (15.92)	132.83 (22.00)	0.43
	70-79	118.30 (16.93)	121.70 (25.30)	123.00 (22.34)	117.40 (41.40)	0.56
Tracking deviation[5] (with out unit)	60-69[#]	11.30 (3.50)	10.90 (5.50)	9.35 (2.75)	8.30 (4.10)	0.16
	70-79[#]	13.48 (4.69)	13.50 (3.57)	15.57 (6.61)	12.90 (2.40)	0.68

[1]Standard deviation;[2]Interquartile range; [3]Visual stimuli; [4]Hearing stimuli; [5]Distributed attention capacity; [#]Difference between medians.

DISCUSSION

The objective of this study was to compare the cognitive and perceptive motor performance of physical activity practicing and non-practicing elderly, considering some variables, which may influence this result. In this study, the performance of both groups was similar, including means and medians for the CG, in some variables (mainly for attention, p<0.01). Thus, it is accepted the interpretation that physical activity can generate benefits to the cognition of older people, but it can't be neglected the existence of other factors influencing these performances that are present in the daily life of the elderly.

Indications from the American College of Sports Medicine suggest that the regular practice of physical activity (PA) helps to maintain and stimulate the cognitive domains in the elderly[6] and may delay the progression of cognitive impairment. However, there is no consensus on the dose needed to achieve these goals[6]. The same authors reinforce that for the effective action of PA in maintaining cognitive performance in the elderly, it is important to ensure that the intervention contemplates and aligns coordinative, aerobic and force stimuli. Even with potential results when such stimuli are combined with mental training[22].

Regarding regular PA, a review of the literature[2] shows that better performances of cognitive functions occur in elderly with better aerobic capacity. In this study, only active physical activity levels were considered through the IPAQ for the characterization

of the active groups without evaluating effectively the aerobic capacity of the evaluated individuals. Moreover, the literature indicates only the domain "level of leisure physical activity" as a factor most related to the functional aptitude of the elderly[23], which makes us reflect on the dose / response of physical activity necessary to positively influence the cognition of these individuals. When considering the time of each gym class, 50 minutes, it is assumed that the weekly frequency of classes to positively benefit the cognition should be three classes and not two, as in this study. However, this assumption has not been analyzed in this work.

In view of the similarity in the psychomotor performance of the elderly, it is possible to emphasize the possibility of not having dedicated a level of attention necessary to the activities during the classes. In gymnastics groups, besides the high number of participants, during the classes (close to one hundred participants / class), there was no measurement of the exercise intensity, which may have affected the results. In addition, the literature has shown that exercise protocols that can include challenging coordinative function activities and close to the day-to-day motor requirements associated with training (known as dual tasks) have presented better results to the individuals' cognition when compared to training force or aerobic only[22]. Such statements are in line with findings in the work of Yokoyama et al.[4] in which when comparing an intervention with aerobic PA and resistance training with an intervention that combined cognitive stimuli, during the practice of PA, it obtained better results for the work of double assignment

Although there is a vast literature on cognitive and emotional correlates of PA and physical fitness, there is a lack of information on how PA affects the biological properties of the human brain[24]. Moreover, studies show that not only the regular practice of PA but also a good cultural and educational level can protect against cognitive deficits in aging[24]. One of the reasons, perhaps, for the lack of difference in cognitive performance between groups may be due to differences in the level of schooling. In CG, there was a higher proportion of older people with a longer formal education, in CG2, for example, 60% of the group declared to have higher education, in contrast, in GG2 all participants studied up to high school (p=0.02).

According to Nascimento et. al.[25], access to schooling serves to improve cognitive function and may also slow mental decline in recent years, creating a cognitive reserve capacity[26]. Moreover, Domiciano et al.[27] add that the speed of processing, attention, intelligence, executive functions and memory are sensitive to schooling, and their performance increased the longer the schooling process was.

In addition to the level of schooling, other variables may also influence the incidence of cognitive decline in the elderly, for example, economic income. A study by Sposito, Neri and Yassuda[28] with Brazilian elderly identified worse results in cognitive performance for those who received between one and three minimum wages. According to them, the preservation of cognitive function in aging is related to environmental opportunities modulated by socioeconomic aspects. In the present study, GG declared a lower economic income, especially GG1, in which almost 65% reported a family income of less than three minimum wages (p<0.001). Following the perspective of Nascimento et al[25], who evaluated the prevalence and factors associated to cognitive decline in the elderly with low economic status, access to schooling, income and healthy life habits can positively influence the preservation of the cognitive abilities of the elderly.

During aging, there may be a decline in the ability to see from a distance, to distinguish objects, to estimate distances, to perceive depths. This impairment may result in difficulties in the tasks of motor precision, relative position and depth impairing the performance of visuo-perceptive and constructive tasks[29]. Although, according to the authors, most neuropsychological tests that evaluate visuospatial functions also require other cognitive abilities. In the present study, the visual field variable also presented similarity in its results. However, based on the research of Yip et al.[30], physical exercise may facilitate ocular blood perfusion, decreasing the incidence of glaucoma, and even attenuate visual field loss[31].

A secondary variable, the tracking deviation, was extracted from the peripheral perception test,

which measures the assessed attention capacity of the assessed. In this test, the active elderly group (in the first decade) presented better performance (p=0.16), suggesting a better ability to distribute attention when asked to perform two simultaneous tasks, but without significant differences. The ease of better distributing attention can be very useful in everyday activities, such as working in hectic or noisy environments, and guiding a car, activities considered difficult for the elderly. It is understood, then, that this supposed superiority of performance can help to keep the practicing individual of PA more socially participatory than those who do not practice physical activity.

Among the limitations of this study there are the differences between level of schooling, social income and non-measurement of the functional ability of the studied group, since it is understood that they can affect the investigated variables. In addition, since this is a cross-sectional research, it is not possible to make a longitudinal evaluation of cause and effect, and the results presented here are subject to other interpretations.

However, the results obtained are a reference for health management, especially physical education professionals, in order to sensitize them to look and improve the interventions offered to the elderly, considering the possibility of allying exercises and strategies to the activities performed during the practice of PA. At the social level, the implementation of physical / cognitive exercise programs becomes of important relevance for the improvement of public and collective actions offered to the elderly. Social actions, which stimulate the resumption of studies for the elderly, can be an essential part of the rehabilitation and maintenance of the cognitive functions of the elderly.

CONCLUSION

This study found no evidence that regular physical exercise can generate some cognitive benefit in healthy older adults when compared to older people who did not practice physical activities regularly. It should be considered that other aspects such as economic income and schooling can influence the cognitive performance of the elderly, overcoming the practice of physical exercises. Other studies that also examine possible cognitive-moderating variables are needed to more accurately show the benefits of aerobic training in promoting cognition of the elderly.

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Quality of life of patients with lung cancer: A scoping review

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Abstract

Objective: To characterize scientific publications on the quality of life of people with lung cancer in order to explore current knowledge of the subject, with emphasis on assessment instruments and methodological aspects. *Method*: A scoping type literature review was performed. Articles were sought in the databases of the Virtual Health Library, in an integrative manner, with the descriptors: Quality of life and Lung Neoplasms, with no date of publication or language restrictions (n=138). The selection of articles was based on inclusion and exclusion criteria defined in the study proposal. *Results*: We included 18 publications published between 2006 and 2017, the majority (n = 10) of which had a cross-sectional design. Eight different instruments were used to evaluate the quality of life of patients with lung cancer, four of which were specific for people with cancer. There was a prevalence of the use of the *European Organization for Research and Treatment of Cancer Care Quality of Life Questionnaire* - EORTC QLQ-C30 (n=8). Prospective studies (n=8) assessed quality of life before and after chemotherapy, physical therapy or pulmonary resection. The studies adopted different methodologies and provided conflicting results of quality of life. Cross-sectional studies with comparatively healthy subjects found an inferior quality of life for people with lung cancer. *Conclusion*: The scoping review contributed to the identification of the multiple evaluated instruments, both generic and specific. It found a lack of homogeneity in the methodological approaches of the studies. Further prospective studies with a specific instrument and methodological standardization to evaluate the quality of life of people with lung cancer are recommended.

Keywords: Quality of Life. Lung Neoplasms. Bibliometrics. Health of the Elderly. Aged, 80 and over.

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INTRODUCTION

Lung cancer became a frequently detected condition among the global population in the 20th century, and as a result, a significant cause of mortality around the world[1]. The disease mainly affects the elderly, with most cases diagnosed in people 65 years of age or older[2], while around half of patients are over 70[3]. In Brazil, it is estimated that there will be 18,740 new cases in men and 12,530 cases in women in 2018-2019[4].

Lung cancer carries considerable weight in the main cancer-related statistics. It is a significant tumor due to its high mortality rate in every country. In addition, the quality of life (QoL) of patients may be affected by different factors, such as the stage of the disease and the type of treatment, as well as individual aspects, causing a negative impact on disease outcomes. Hence the importance of evaluating the QoL of this target group[5], preferably using specific instruments for the disease, taking into account aspects related to cancer such as coughing, fatigue and tobacco use.

Among the specific instruments cited are the Functional Assessment of Cancer Therapy-Lung (FACT-L), which contains questions about symptoms, cognitive function and smoking habits[6]. Also worthy of note is the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire and Lung Cancer Module (QLQ-LC13), which supplements QLQ-C30, both of which have been developed and validated for people with lung cancer and for use in an international context. QLQ-LC13 assesses aspects related to symptoms and the side effects of treatment[7].

QoL is a broad concept and was developed through the initiative of the World Health Organization (WHO), in the development of the generic World Health Organization Quality of Life (WHOQoL) instrument. The WHO defined QoL as the "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"[8]. Therefore, the concept is subjective and relates to different aspects of life, degree of satisfaction, whether in one's family, love, social and environmental life, and the existential esthetic[9].

When this broad concept is transferred to health, it becomes health-related QoL. It can be affected by alterations caused by damage to one's functional state, perceptions and social factors, influenced by diseases/harm, treatments and health policies. Thus, the concept can also be delimited by the interference of disease in the lives of individuals[9], which justifies the need for specific instruments for a particular disease.

A greater understanding of quality of life and lung cancer will support professionals in managing the clinical care of these patients, as well as future studies. The present study aimed to characterize relevant scientific publications to explore current knowledge about the quality of life of people with lung cancer, with an emphasis on assessment instruments and methodological aspects.

METHOD

A scoping review study was carried out. This type of study recognizes a topic that has not yet been addressed by a systematic review, or that has a complex and heterogeneous nature, making it difficult to more accurately review the evidence. This method helps to identify gaps in knowledge and to propose recommendations for future research. The study followed the following projected steps: (1) identification of the research question; (2) identification of relevant studies; (3) selection of studies; (4) data mapping; (5) comparison, summary and reporting of results[10]. The following question was defined: What is the current knowledge about the QoL of patients with lung cancer, the evaluative instruments and the methodological aspects of the studies?

The search for references was performed in the regional Virtual Health Library (VHL), as it integrates content on a specific theme from different countries. The databases were consulted in an integrative manner (patients with lung cancer AND quality of life) AND (instance: "regional"), without date of publication or language restrictions. The 14 bases of the VHL (international and Brazilian) in the area of

Health Sciences include Lilacs (Latin American and Caribbean Literature in Health Sciences), Medline (Medical Literature Analysis and Retrieval System Online), SciELO (Scientific Electronic Library Online), the Cochrane Library, BDENF (Nursing Database) and IBECS (Spanish Bibliographical Index of Health Sciences). The search took place in December 2017 and was updated on August 29, 2018. Portuguese descriptors were used. The VHL retrieves publications in any language, in addition to that used, in Portuguese, English or Spanish. Even with Medline, in which most of the texts are in English, the use of any of the three languages mentioned is recommended when searching by subject descriptor (https://bvsalud.org/como-pesquisar/).

The inclusion criterion for selection by title/abstract was: Theme of QoL in people with lung cancer. The exclusion criteria were literature/theoretical review articles, duplicity in different databases, articles taken from the same research, studies with the principal objective of validating instruments by correlations of items/domains; case/experience reports; research and study protocols with the central purpose of comparing treatment modalities, with QoL a background variable.

The selection of the material was performed by two researchers, individually and independently (Figure 1), without disagreement between evaluators (kappa=1).

Qualitative analysis was carried out through the characterization of the publications. The data of interest were: author(s)/year; journal; language; population (age), place of recruitment; state/country; study design; assessment instruments and synthesis of results. Comparative cross-sectional and longitudinal studies were assessed for methodological quality by the Newcastle-Ottawa Scale (NOS) scale, which provides scores up to nine points and where a higher score reflects better quality. This scale considers three methodological questions: Participant selection, statistical comparability between groups and exposure/outcome items[11]. For comparative cross-sectional studies the case-control scale was adapted, and for prospective studies, the cohort scale.

RESULTS

As shown in Figure 1, 18 articles[5,9,12-27] were selected for review.

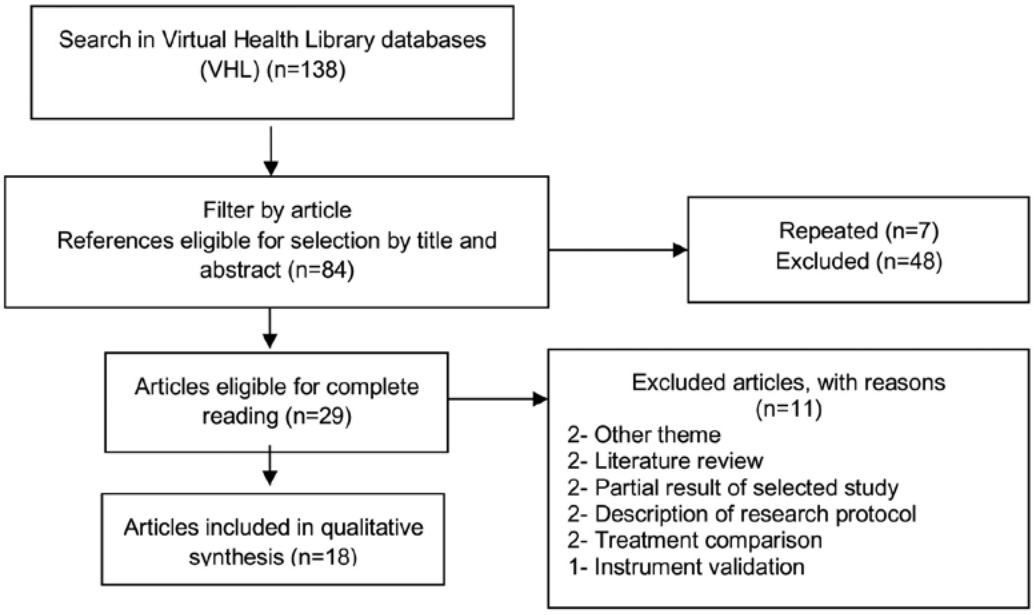

Figure 1. Flowchart of search process of study carried out in Universidade Estadual de Montes Claros, Minas Gerais, Brazil. 2018.

Chart 1 characterizes the studies published between 2006 and 2017. A total of 44.4% were published in English and 55.6% in Portuguese.

Five studies[13,16,19,25] included individuals with other types of cancer. In 94.4% (n=17), the samples were convenience based, recruited in hospitals or cancer centers. A cross-sectional design was adopted in 55.6% (n=10) of the studies. Non-controlled prospective, "before and after" studies assessed QoL before and after chemotherapy[9,14], before three cycles of chemotherapy[26], before and after lung resectioning[21,22], before and after physiotherapy[20], before starting treatment and two and four months after the first evaluation and/or the beginning of treatment[27].

The researchers used eight instruments (Chart 2).

Chart 3 describes concurrent (n=7) and cross-sectional (n=2) prospective studies in terms of QoL instrument, affected domains, and assessment of methodological quality. The loss of quality of the studies, in general, is due to convenience sampling; self-reported information; disease already established at the beginning of recruitment and lack of multivariate analysis.

Chart 1. Description of studies included in scoping review in descending chronological order based on year of publication, 2017-2006.

Authors, Year	Study design	Population age and/or (mean ± standard deviation years)	Place of patient recruitment/Country/Year of data collection
Borges et al., 2017[24]	Cross-sectional	Patient-caregiver dyad Patient: (65.2±11.1) Caregiver: (47.6±13.2)	Oncology outpatient clinic of university hospital of Universidade Federal de São Paulo (Unifesp), in the city of São Paulo, Brazil. Year of data collection not stated.
Fiteni et al., 2016[23]	Cross-sectional (*baseline* of a clinical trial)	Patients aged 70-89 years	From a wider study in France. Year of data collection not stated.
Nai-Wen et al., 2015[12]	Cross-sectional	Patients Men: (62.8±10.6) Women: (61.6±9.8)	Two teaching hospitals in Taipei, Taiwan, 2012.
Ferreira et al., 2015[9]	Longitudinal	Patients 61-79 years (69.4±5.7)	Unified Health System (or SUS) Hospital, Recife, Pernambuco, Brazil, 2012.
Frio et al., 2015[25]	Cross-sectional	Patients (64.24±11.69)	Chemotherapy service of Hospital School of Universidade Federal de Pelotas, Rio Grande do Sul, Brazil, 2008 to 2010.
Avelino et al., 2015[26]	Study of multiple cases	Patients (66±11.1)	Public hospital in Rio de Janeiro, Brazil, 2013.
Nicolussi et al., 2014[13]	Cross-sectional	Patients aged 18 to over 80, with 39.5% aged ≥60 years.	Specialized Oncology Center (or CEON) of Hospital Sociedade Portuguesa de Beneficência and Chemotherapy Center of HC-FMRPUSP, Brazil, 2009-2011

to be continued

Continuation of Chart 1

Authors, Year	Study design	Population age and/or (mean ± standard deviation years)	Place of patient recruitment/Country/Year of data collection
Muller et al., 2014[27]	Longitudinal	Patients aged 43-81 years Surgical group(64.7±10.1) and non-surgical group (62.8 ± 9.4)	Clinical hospital in Porto Alegre, RS, Brazil, 2009 to 2010.
Oliveira et al., 2013[14]	Longitudinal	Patients 51-87 years (68±8.8)	Public hospital in São Paulo, Brazil, 2007-2009
Franceschini et al., 2013[15]	Cross-sectional	Patients (61.3±10.1)	Oncology-pneumology Outpatient Clinic of Hospital São Paulo (Unifesp) in São Paulo, Brazil. Year of collection not stated.
Pastore, Oehlschlaegere and Gonzalez, 2013[16]	Cross-sectional	Patients (63.9±11.6)	Chemotherapy service of Hospital School of Universidade Federal de Pelotas (Rio Grande do Sul), Brazil, 2008-2010.
Floyd et al., 2011[17]	Cross-sectional	Patients 41-84 years (64±9.12)	Regional Cancer Center in USA, Year of collection not stated.
Weaver et al., 2011[19]	Cross-sectional	Patient-caregiver dyad. Minimum age not stated, maximum ≥80 years. 53.1% ≥66 years.	Database: National Cancer Institute Cancer Care Outcomes Research and Surveillance (CanCORS), USA, 2004-2005
Lee et al., 2010[18]	Cross-sectional	Patients and healthy controls in database of 2001 National Health Survey. Patients: 30-85 years (63.6±11.0) Controls: 32-65 years (57.2±6.7).	National Taiwan University Hospital (NTUH), Taiwan, 2002
Ozalevli et al., 2010[20]	Longitudinal	Patients 53-83 years (66.17±7.33)	Chest Diseases Department of Dokuz Eylul University, Turkey, Year of collection not given.
Lima et al., 2009[21]	Longitudinal	Patients 39 to 79 years (60.18±11.59)	Thoracic Surgery Department Hospital A. C. Camargo de São Paulo, Brazil, 2006-2007.
Franceschini et al., 2008[5]	Longitudinal	Patients and individuals without cancer Patient: (61.3±16.4). Control: (60±12.2)	Oncology-pulmonology outpatient clinic of Hospital São Paulo (Unifesp) Brazil, Extra Penha Exercise Group (controls), Brazil, Year of collection not given.
Saad, Botega and Toro, 2006[22]	Longitudinal	Patients 18-78 years (55.5±13.4)	Clinical Hospital of Universidade Estadual de Campinas, Brazil, 2001-2003.

Chart 2. Instruments used to assess quality of life according to functions and items.

Instruments for assessment of quality of life	Functions/items of assessment of instruments
European Organization for Research and Treatment of Cancer Care Quality of Life Questionnaire (EORTC QLQ-C30[9,12-16,23,25,26]	Specific instrument for cancer. Contains 30 assessment items: a General Health/Quality of Life scale; five functional scales (physical, cognitive, emotional, social and role performance functions); eight symptom scales (fatigue, pain and nausea and vomiting, dyspnea, loss of appetite, insomnia, constipation and diarrhea) and an item assessing the financial impact of treatment and illness.
Quality of Life Questionnaire Lung Cancer Module (LC-13), version 3.0[14,26]	Specific instrument for lung cancer. Complementary module of EORTC QLQ-C30. Contains 13 assessment items based on symptoms associated with lung cancer: a dyspnea and other items scale (cough, hemoptysis, dyspnea and pain at specific site), treatment-related effects (sore throat, dysphagia, sensory neuropathy and alopecia) and pain management.
Functional Assessment of Cancer Therapy-Lung (FACT-L)[15,17]	Specific instrument for assessment of lung cancer. Contains 36 assessment items. The instrument is subdivided into four main quality of life domains: physical, social/familial, emotional and functional) plus nine specific items for lung cancer.
Saint George's Respiratory Questionnaire (SGRQ)[21]	Specific instrument for chronic obstructive pulmonary disease. Contains 76 evaluation items. Addresses aspects from three domains: symptoms, activity and psychosocial impacts of the respiratory disease on the patient.
Medical Outcomes Study 36-item Short-form Survey (SF36) [5,15,21,22,24,27]	Generic quality of life instrument. Contains 36 assessment items. Consists of eight domains: functional capacity, physical functioning, body pain, general health, vitality, social aspects, emotional function and mental health; and one question aimed at the comparative evaluation of current health conditions and conditions a year ago.
Medical Outcomes Study 36-item Short-form Survey (SF12)[19]	Generic instrument of quality of life. Short version of the SF 36 instrument described above. Contains 12 items that address the physical (functional capacity and limitations by physical aspects) and mental components (pain, vitality, social aspects, limitation by emotional aspects and mental health).
World Health Organization's Quality of Life (WHOQoL-BREF)[18]	Generic instrument of quality of life. Contains 26 items, two of which are general quality of life and the others which represent each of the 24 facets of the instrument, classified into four main domains: physical, psychological, social and environmental.
Nottingham Health Profile (NHP)[20]	Generic quality of life instrument. Contains 38 items Self-administered questionnaire, with answers in yes/no format. Items organized into six categories including: energy level, pain, emotional reactions, sleep, social interaction and physical abilities.

Chart 3. Description of prospective and cross-sectional comparative studies according to quality of life (QoL) instrument, affected domains and evaluation of methodological quality.

Authors and year of prospective concurrent studies	**Instrument used to assess QoL**	**QoL domain affected. Results of prospective studies following chemotherapy, physiotherapy and pulmonary resection**	*Newcastle-Ottawa* **Scale**
Ferreira et al., 2015[9]	European Organization for Research and Treatment of Cancer Care Quality of Life Questionnaire - EORTC QLQ-C30	After chemotherapy there was a decline in physical performance. However, there was no change in QoL.	6(9)
Avelino et al., 2015[26]	EORTC QLQ-C30 Lung Cancer Module (LC-13)	After three cycles of chemotherapy, with an interval of 21 days. There was improvement in the physical capacity scale and a deterioration in the cognitive scale. The items that showed improvement were: pain, pain in the chest and in the arm or shoulder and loss of appetite.	4(9)
Muller, Silva and Xavier, 2014[27]	Medical Outcomes Study 36-item Short-form Health Survey (SF-36)	There was no difference in QoL after the start of chemotherapy or 60 and 120 days after the first evaluation. The population was divided into two groups: surgical and non-surgical. No difference in QoL between groups.	4(9)
Oliveira et al., 2013[14]	EORTC QLQ-C30 and LC-13	After chemotherapy, there was an improvement in the QoL of the symptoms of dyspnea. After chemotherapy there was improvement in the symptoms of hemoptysis and a worsening of alopecia.	5(9)
Ozalevli et al., 2010[20]	Nottingham Health Profile (NHP)	After physical therapy there was an improvement in cancer patients in terms of physical mobility, pain, energy, emotional aspects and sleep.	6(9)
Lima et al., 2009[21]	Saint George's Respiratory Questionnaire (SGRQ) and SF-36	After pulmonary resection the results for the symptoms, activity and impact domains were worse in comparison with the overall Spanish population. After pulmonary resection, there was no difference in QoL when compared to a healthy control population.	4(9)
Saad, Botega and Toro, 2006[22]	SF-36	After pulmonary resection there was an improvement in QoL in the social domains 90 days after surgery; physical and functional performance in the individuals, with better performance in the walking test and forced vital capacity; and in the physical domain in cases with reduced pulmonary resection.	7(9)
Authors and years of cross-sectional comparative studies	**Instrument used to assess QoL**	**QoL domain affected. Results of comparative cross-sectional studies**	
Lee et al., 2010[18]	World Health Organization's Quality of Life- WHOQoL-BREF	Compared with healthy people, there was no difference between the QoL of patients with cancer in the social and environmental domains. The QoL of patients with cancer was worse in the physical and psychological domains. Patients with cancer had worse scores in the self-assessment of overall health and QoL.	6(9)
Franceschini et al., 2008[5]	SF-36	QoL in the SF-36 domains was worse in patients with lung cancer than in healthy patients.	7(9)

Comparative cross-sectional studies[5,18] with individuals without cancer revealed a worse QoL among cancer patients.

QoL was evaluated before and after chemotherapy[9,14,26,27] with varying assessment frequencies in patients with cancer stages I to IV.

A study by Saad, Botega and Toro[22] evaluated QoL before surgery and 30, 90 and 180 days later. In the prospective cohort study by Lima et al.[21], QoL was evaluated only six months after pulmonary resection.

The evaluation of patients before and after physical therapy[20] involved advanced stages of cancer (III B or IV).

DISCUSSION

This review described the characteristics of studies of the QoL of patients with lung cancer, identified the QoL instruments used and explored the methodological aspects of the research, as well as evaluating its quality. The elderly are more affected by lung cancer[2,3], which explains the age of the patients, which was generally over 60 years. Being elderly is a risk factor for lung cancer, with such individuals having a 4.33 times greater chance of having the disease than those at other ages[28]. Greater life expectancy allows sufficient time to develop the disease[29].

The QoL instruments were generic and specific. The generic studies evaluate QoL irrespective of the presence of the pathology. The specific studies analyzed patients with cancer of any type, with lung cancer and with chronic obstructive pulmonary disease.

Eight different instruments evaluated the QoL of patients. The most frequently adopted was specific for people with cancer, EORTC QLQ-C30, although it was used in less than half of the articles. Its LC-13 complementary module was used in two studies[15,26] because it is specific for lung cancer, evaluating QoL for the particular symptoms of this disease. It is therefore recommended to combine these scales.

These instruments are potentially useful because they are based on life and health symptoms and impairments which affect patients. An instrument such as the EORTC QLQ-C30[9,13-17,23,25,26] evaluates fatigue among the symptoms of patients with cancer. In a literature review it was observed that fatigue impacts the QoL of patients with lung cancer. It influences the execution of activities of daily living, relapse of the disease, the reduction of survival and emergency care and hospital admissions. It is highly prevalent and needs to be better evaluated through studies with high levels of scientific evidence[1]. It should be considered that elderly patients usually suffer reduced functional capacity[30-33], which, added to the fatigue caused by the disease[34], may result in greater impairment of activities of daily living and interference in QoL[35-37].

Specific instruments with varying purposes were noted, for example, the evaluation of chemotherapy (Quality of Life Questionnaire for Cancer Patients Treated with Anti-Cancer Drugs (QoL-ACD) and those which featured treatment side effect items. However, it should be emphasized that this instrument would not be suitable for individuals at the initial stage of the disease who are treated by surgical resection. In this situation, generic instruments or those specific for respiratory diseases are recommended. It is the responsibility of researchers to choose the best instrument or to use more than one. In Brazil and in developed countries, about 70% of patients have advanced (stage III) or metastatic (stage IV) lung cancer[39] and it can be inferred that for most studies specific instruments are recommended, since the patients diagnosed would already be living with symptoms and their implications for QoL.

Among the non-specific instruments, the SF-36, used in six studies, is worthy of note. It assesses both the negative (illness/infirmity) and positive (well-being) aspects of health[15]. Generic instruments perform multidimensional health assessment, identifying the ability to perform activities of daily living. Applied at different times, they assess improvement or worsening in physical and emotional aspects. In this sense, generic instruments can be useful for evaluating a certain intervention[40].

However, assessment involves general aspects of life and does not consider disease specificities, such as in the QLQ-LC13, with items for symptoms and the adverse effects of treatment such as coughs, mucositis, alopecia and chest pain[15,26].

The prospective studies assessed QoL, before and after: chemotherapy, physiotherapy or pulmonary resection. They adopted generic and specific instruments. In one study, antineoplastic chemotherapy worsened the physical performance of patients[9]. Also, in the study by Nicolussi et al.[13], cancer and its treatment affected patients in some way, causing deterioration in the functions performed and the presence of more symptoms, impairing QoL. However, improvement in QoL may occur if the side effects of treatments can be avoided and controlled and there is adherence to effective complementary treatments that can assist in coping with the disease and treatment[13].

However, Oliveira et al.[14] found an improvement in QoL and symptoms of dyspnea and hemoptysis after chemotherapy. In the study by Avelino et al.[26], the authors found differences in QoL regarding physical and cognitive capacity during chemotherapy, with improvement and deterioration, respectively. They also observed improvement in pain and loss of appetite. The study by Muller, Silva and Xavier[27] showed no difference in QoL before chemotherapy and 60 and 120 days later. The negative effects of adjuvant chemotherapy on QoL appear to be temporary and improvements are common in most patients[41].

The evaluation of QoL after physical therapy was described in one study, with improvement in physical mobility, pain, energy, emotional aspects and sleep[20]. The results after pulmonary resection are contradictory[21,22], with both deterioration[21] and improvement in QoL[22]. Studies comparing the QoL of people with cancer with healthy individuals[5,18] found a worse overall QoL score for cancer patients in the SF-365 and WHOQoL-BREF[18]. In the latter study[18] there were worse scores in the physical and psychological domains.

Despite the lack of consensus on the type of instrument adopted, evaluations of QoL can be an important tool for guiding health interventions in the affected QoL domains, according to the chosen therapy and clinical evolution of the patient, in a given context.

Regarding the losses in quality of the articles, given the severity of the disease, the most practical way to recruit participants is in the hospital environment, explaining the use of convenience samples. Quality of life is subjective in nature, and it is therefore feasible that the responses to the instruments should be provided by self-assessment. It should be noted that the instruments provide quantitative data in different domains, which is useful in comparing procedures and population groups, supporting decision-making in health care and future investigations.

Limitations of the present study include the fact that the search was carried out only in the VHL and in Portuguese. However, the importance of the regional VHL is highlighted, as it incorporates more than 30 databases, including 14 from Health Sciences, such as Lilacs and Medline. It is important to emphasize that in the VHL, even with descriptors in Portuguese, searches are made for publications in other languages and in other countries. In addition, the VHL is supported by the technical cooperation of the Pan-American Health Organization.

CONCLUSION

This scoping review identified discrepancies between the prospective studies evaluating quality of life after chemotherapy and pulmonary resection, which found both deterioration and improvement in QoL. The probable causes of this are methodological diversity, with different questionnaires applied across varying treatments and frequency reapplications, and the use of convenience samples of different ages and stages of disease. This does not help when grouping results in meta-analysis, which justifies the use of the scoping review method when exploring publications in terms of the methodological aspects and instruments used.

The results of the comparative cross-sectional studies should be evaluated with caution. They compare diseased and healthy populations and use

generic questionnaires, such as the WHOQoL-BREF and SF36. They identified a worse quality of life in the overall score of the instruments for people with cancer. A study with the WHOQoL-BREF also found worse results in the physical and psychological domains, with no differences in the social and environmental domains. This is most likely due to the lack of disease specificity in the questionnaire, which includes domains that evaluate sexual activity and aspects of health care, such as the availability and quality of care, which are commonly affected by the disease; especially in studies with patients in advanced stages.

The choice of generic instruments to evaluate quality of life in patients diagnosed with cancer should not be encouraged, as the disease carries particularities that impact the life of the patients, and this theme can be better evaluated by specific instruments. Such assessment should preferably be complemented with evaluation by specific instruments for people with lung cancer, which consider, in addition to functional, emotional and social aspects, the symptoms associated with lung disease. These instruments better evaluate the impact of lung cancer on the quality of life of the individual.

Further studies with a specific instrument for people with lung cancer are therefore recommended. Prospective studies should also be encouraged, as they allow the evaluation of quality of life at different times. Different cancer modalities should not be grouped together, due to their specificities and possible impairment in different aspects. Methodological homogeneity should be applied, analyzing groups by age, disease stage and treatment modalities, while consensus should be sought among experts regarding the best timing/frequency of the application and reapplication of the instruments.

It is also recommended, where possible, that respondents are randomly selected, as the convenience sample method limits generalizations of the results by restricting the participation of those with advanced physical disability or cognitive impairment, resulting in an overestimation of the quality of life. The exclusion of comorbidities that can influence quality of life should also be considered in future studies.

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