Cogitare Enfermagem

THE ELDERLY NEEDS IN SELF-MANAGEMENT OF CHRONIC DISEASE: ENVISIONING A NURSING INTERVENTION PROGRAMME

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ABSTRACT

Objective: To characterise the health profile of community-dwelling older people and identify the domains of the disease self-management process for nursing interventions. Method: Mixed-method study, with 48 participants from Porto, Portugal, between September 2018 and July 2019. A questionnaire was used to assess disease and health-related variables, and a semi-structured interview was also undertaken focused on chronic disease self-management. Qualitative data were submitted to thematic content analysis. Results: 93.7% of participants present comorbidities, mainly cardiovascular and endocrine diseases. Three themes emerged from the interviews: Mastery in the management of medications; Difficulty in adopting a stable, healthy behaviour; Importance of a close and trusting relationship with health professionals. Conclusion: The self-management needs of older people that can be diminished through nursing interventions were highlighted, emphasising areas to be intervened and strategies to be used in programmes aimed at promoting the health literacy of this population.

DESCRIPTORS: Elderly; Self-management; Chronic Disease; Ageing; Nursing.

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INTRODUCTION

The ageing of the world's population has been a growing phenomenon in recent years[1,2]. In Portugal, the group of people aged 65 years or more accounts for 22% of the current population, and the ageing index (number of elderly per 100 young people) is 161[3]. The increasing life expectancy does not necessarily relate to living more years in a healthy condition. The ageing phenomenon is accompanied by an increase in chronic diseases[4] that can likely limit the functional status, productivity and quality of life of chronically ill people[5].

Ageing implies an increased risk for developing vulnerabilities, which involve a set of individual and collective aspects that influence living and health conditions[6], making the elderly a particularly vulnerable group in need of support to live healthier and reduce the impact of chronic diseases. Thus, programmes and community interventions for people with chronic diseases should be planned, developed and implemented, under the joint efforts of health care systems, social organisations and the academic community[5].

Within a broader research project called "PT4Ageing: Personal Trainer for health management of older people", an intervention programme focused on self-management of chronic disease will be developed. Since the evidence in this domain is scarce in Portugal, it was decided to develop a first characterization study of the target population.

The emerging phenomenon of population ageing challenges the implementation of sustainable policies in the current and future society[7], promoting healthy ageing[1,2]. Healthy ageing is a lifelong process and goes beyond the absence of disease[2]. However, alongside ageing and changing lifestyles, there is also an increase in chronic diseases[4,8], associated with increased morbidity and mortality, particularly in older people[9].

According to the "Health Portrait 2018" [Health at a Glance][10], the Portuguese population is currently living more years, but with more years lived with disability (YLD) for people aged over 65 years old, compared to other countries of the Organisation for Economic Co-operation and Development (OECD). The elderly in Portugal present more comorbidities, especially diabetes, cardiovascular diseases, obesity and oncological diseases[10].

The elderly with health problems have increased demands for more health care and social support[7]. In Portugal, the sociodemographic characteristics of the elderly population render this group more vulnerable. Among these characteristics, some are particularly important, such as the low literacy, low economic resources and lack of access to social structures, which often replace the support for physical and psychosocial needs, at a stage of life where close informal support networks are disappearing[3,10]. Given the existence of comorbidities with the need for polymedication, disease management becomes even more complex in this age group[10]. The role of health professionals in this field is crucial, with particular emphasis on nurses' intervention.

The World Health Organization identifies the need for new models of health promotion and disease prevention for the elderly[2]. In a review study, effective self-management programmes are identified, producing modest but clinically significant results on indicators such as health behaviours, health status, self-efficacy and quality of life, and also a decrease in the utilization of health care[11]. The effectiveness of these programmes depends mainly on the early identification of the specific needs of the target elderly populations. In a qualitative study developed in the United States of America (USA) on the experience of older people with multiple chronic diseases, several needs were identified, such as the emotional difficulties associated with symptoms (e.g., anxiety and sadness), the functional implications of diseases that threatened the well-being and factors related to health care, including difficulties in obtaining information or difficulties in communicating with health professionals[12].

When characterising the elderly population concerning chronic disease management, in addition to clinical indicators, such as the presence of pathologies and symptoms, it is important to assess the elderly self-perception of health and disease self-management process. Therefore, collecting data that reflect the experiences of the elderly in these areas and identifying the needs for which nurses can be a resource is of the utmost importance. The self-perceptions of the elderly are multifaceted and complex and can influence well-being and quality of life[13].

According to a review study, support programmes for the elderly do not always use strategies to deal with the impact of diseases on their daily lives. Thus, the authors point out that the programmes should be tailored to the needs of the elderly with multiple diseases and assess whether participants are using the proposed strategies[14].

In Portugal, the scarcity of evidence in this area led to the development of the present study that aims too characterize the elderly population with chronic disease in order to support the development of such a programme. Therefore, this study aims to characterize the health profile of community-dwelling older people and identify the domains of the chronic disease self-management process for nursing interventions.

METHOD

A mixed-method study was conducted between September/2018 and July/2019 in a health care facility in the urban region of northern Portugal. A non-probabilistic convenience sample included 48 older people from the community recruited from health care institutions (USF and UCC) of the city of Porto.

Inclusion criteria were: being 65 years of age or older; living in the community; with at least one chronic disease; with mobility attend the sessions in the health unit; without cognitive deficit. All the elderly answered a questionnaire, but only four participated in the semi-structured interview. The administration of the questionnaire and interviews were conducted in the health units, in a private room, by collaborators who received training before data collection.

Several instruments were included in the questionnaire used for data collection, namely for socio-demographic and clinical characterisation, self-perceived health, individual lifestyle profile, treatment adherence and quality of life. The interview was performed with a script.

The instrument for sociodemographic and clinical characterization was specifically designed for this study, and assessed variables such as gender, marital status, education and the presence of diseases and symptoms. In addition, self-perceived health was assessed by a question: "In general, how would you evaluate your health?", scored on a 5-point Likert-type response scale: "one=Poor"; "two=Acceptable"; "three=Good"; "four=Very Good"; "five=Excellent".

The individual lifestyle profile adapted for this study is composed by the following subscales "Diet"; "Physical activity"; "Preventive behaviour"; "Social relationships"; and "Stress management". The internal consistency of the total scale is 0.91. It has a four-point Likert-type response scale, in which the higher total score obtained, the greater the adherence to the specific lifestyle.

The Measurement of Adherence to Treatments (MAT) is a scale developed by Morisky, Green and Levine in 1986, translated and adapted to the Portuguese population[15]. This scale consists of seven items, in which the respondent is asked about how many times he/she behaves in a certain way concerning a prescribed. The answers are presented on a six-point Likert-type scale, ranging from "one=Always"; to "six=Never". Results are interpreted

with a higher value corresponding to better adherence to the prescribed medication. In this study, the trustworthiness of the MAT Scale was 0.682.

The Portuguese version[16] of the World Health Organization Quality of Life Assessment in Older Adults inventory (WHOQOL OLD) consists of 28 questions, grouped into seven subscales/domains: "Sensory abilities"; "Autonomy"; "Past, present and future activities"; "Social participation"; "Death and dying"; "Intimacy"; "Family/Family life". In the present study, the global scale (28 items) showed an internal consistency of 0.904. The answers were given in Likert-type scale, and the higher the value obtained, the better the perception of quality of life.

The semi-structured interview followed a guide that included several open questions, focused on the description of health status, disease management process, lifestyles and needs felt within the scope of nursing care focused on self-management of chronic disease.

Quantitative data were descriptively analysed using IBM SPSS Statistics, version 25.0 software. The results are presented through absolute and relative frequency, mean and standard deviation. After being transcribed, the interviews were subjected to thematic analysis[17].

This study was approved by the Ethics Committee of the Regional Health Administration of the Northern region of Portugal in January 2018 (Opinion no. 1/2018). Participants were informed about the objectives and purpose of the study and were asked to complete and sign the informed consent.

RESULTS

This study sample was mostly composed of women (n=32; 67%), married or cohabiting (n=27; 56%), and aged between 65 and 90 years, with a mean of 74.9 years (SD=6.80)

The schooling level was low (M=3.65 years; SD=3.82), with a minimum of zero years and a maximum of 18 years. Most participants were retired (n=42; 88%), having worked in different types of professional activities, according to the 2010 National Classification of Occupations. However, two older people reported they were still working (4.2%). The elderly household had a range of one to five members and was, on average, composed of 1.98 (SD=1.06), with only one (2.1%) participant living alone.

The characterization data on the health status of community-dwelling older people showed that the sample presented a set of chronic diseases, the majority with comorbidities (n=45; 94%). It should be noted that 24 participants - 50% of the sample - had two associated diseases. The most common chronic diseases were cardiovascular and endocrine diseases. As expected, the sample participants reported a set of symptoms, being musculoskeletal and osteoarticular pain standing the most frequently reported, followed by impaired vision.

Of the 16 respondents (33.3%) who indicated having pain/sensation or discomfort at the time of data collection, this was located in one or several parts of the body and with a mean intensity of 4.68 (SD=3.19), assessed through the Face Scale, which corresponds to "moderate pain". However, seven patients (14.7%) evaluated their pain as intense (scale values of seven, eight and nine). Medication is related to the participants' chronic diseases, with most taking between two and three medicines in association, resulting in polymedication, as observed in Table 1.

Table 1 – Sociodemographic and clinical characterization of participants (n=48), Porto, Portugal, 2019 (continues)

Variables	n	%
Gender		
Male	16	33,3
Female	32	66,7
Age		
65 – 74 years	29	60,4
75 – 84 years	15	31,3
> 85 years	4	8,3
Marital status		
Married or cohabiting	27	56,3
Widower	15	31,3
Divorced	4	8,3
Single	2	4,2
Schooling		
No schooling (0 years)	15	31,3
First cycle (grades 1 to 4)	25	52,1
Second cycle (grades 5 and 6)	3	6,3
Third cycle (grades 7 to 9)	2	4,2
Upper secondary education (grades 10 to 12)	1	2,1
Higher education	2	4,2
Number of household members		
0	1	2,1
1	17	35,4
2	18	37,5
>3	12	25
Associated diseases		
Cardiovascular disease (stroke, angina pectoris, hypertension)	36	75%
Endocrine disease (diabetes mellitus)	25	52,1
Musculoskeletal and osteoarticular disease (arthritis, arthroses)	21	43,8
Psychiatric disease (depression)	7	14,6
Respiratory disease (COPD, asthma, bronchitis)	6	12,5
Cerebrovascular disease (cerebral vascular accident (CVA)	4	8,3
Oncologic disease	1	2,1
Other diseases (ophthalmologic, gastrointestinal, metabolic – thyroid; neurologic - epilepsy)	8	16,7
Association of one or more diseases (Comorbidities)		
0	3	6,3
1	6	12,5

	n	%
2	24	50
>3	15	31,3
Symptoms		
Musculoskeletal and osteoarticular pain (arthritis, arthroses)	26	54,2
Vision impairment	25	52,1
Pain/sensation or discomfort	16	33,3
Impaired walking	15	31,3
Persistent feelings of sadness	10	20,8
Frequent unbalance	10	20,8
Urine loss/urinary incontinence	8	16,7
Memory changes interfering with daily life	6	12,5
No symptoms	10	20,8
Medication		
Medications for the cardiovascular system	45	93,8
Oral antidiabetics	24	50
Analgesics	10	20,8
Anti-inflammatories	9	18,8
Anti-depressives	9	18,8
Insulin	6	12,5
Sedatives	5	10,4
Medications for the respiratory system	4	8,3
Total medications (in association)		
1	10	20,8
2	19	39,6
3	12	25
>3	6	12,5

Source: Authors (2019).

Based on the objectives of this study, it was also considered appropriate to calculate the descriptive measures of some variables, namely self-perception of health, adherence to treatment (MAT), lifestyles and quality of life (WHOQOL-OLD) as displayed in Table 2.

Table 2 – Analysis of variables, Porto, Portugal, 2019 (continues)

Variables	n	M	SD	Mean	Mode	Min.	Max.
Self-perceived Health	48	2,54	0,82	2	2	1	5
Adherence to treatments (MAT)	48	5,69	0,4	5,86	6	4	6

Lifestyles	Diet	48	1,9	0,73	2	2	0	3
	Physical activity	48	0,82	0,92	0,5	0	0	3
	Preventive behaviour	45	2,16	0,69	2,2	2	0	3
	Social relationship	48	1,72	0,79	1,67	1	0	3
	Stress management	48	1,82	0,68	2	0	1	3
Quality of Life (WHOQOL-OLD)	Sensory abilities	47	16,26	3,14	17	19	9	20
	Autonomy	47	17,81	2,11	18	20	12	20
	Past, present and future activities	46	15,46	2,86	15	15	8	20
	Social participation	48	15,48	3,2	15,5	16	8	20
	Death and dying	47	14,34	4,03	15	16	4	20
	Intimacy	48	15,58	4,56	16	20	4	20
	Family /Family life	48	16,58	3,4	17	20	8	20
	Total	44	111,34	14,93	110,5	109	75	137

Source: Authors (2019).

Concerning self-perceived health, the results indicate that the sample had a perception of health ranging between "Acceptable" and "Good". However, it should be noted that 50% of the sample classified it as "Acceptable" 4.2% as "Poor". Medication adherence scored a mean of 5.69 (SD=0.40). Considering the median value of 5.86, the overall sample showed a high adherence to the prescribed medication.

The participants also reported an healthy lifestyle, mostly related to preventive type behaviours, followed by an healthy diet. On the other hand, poor adherence was found in relation to physical activity. Overall, the participants perceived their quality of life as acceptable/moderate. The results on the subscales/domains showed that the sample perceived a good "Autonomy" and good "Sensory Abilities", as well as a good quality of life in "Family/Family Life". In contrast, low perception of quality of life regarding "Death and Dying" was evidenced.

In order to explore the domains of the chronic disease self-management process requiring nursing intervention, the interviews transcripts were analysed and the following themes emerged: "Mastery in medication management", "Difficulty in adopting a stable, healthy behaviour", "Importance of a close and trusting relationship with health professionals".

Concerning the first theme, "Feeling of mastery in medication management", all participants shared this feeling, claiming to know all their medication and reporting an easy adherence, particularly regarding schedules and ways of administration. The need to make adjustments to the medication regimen was also reported, which, although at the participants' initiative, were later validated by the physician. The following statements illustrate this analysis:

I'm not taking these cholesterol drugs... they suggested the red rice tablets... since it's not a chemical thing... But I've already told the doctor and she knows it perfectly well. (P1)

The doctor told me to take one in the morning and another in the evening. But as I was taking too much insulin, if I forgot to eat something in the morning I would almost faint. So, I decided to start dividing the insulin,... and I divided it three times. I do this on an empty stomach, before lunch, and before dinner. And I've never had any problems since then ...and I told the doctor ...I tried this, and he asked: "do you get along well? So carry

on. Until today. (P3)

The second theme, "Difficulty in adopting a stable, healthy behaviour", was well noted in the reports of the four participants. This theme describes the need for compliance with health behaviours usually present in the non-pharmacological component of the therapeutic regimen, mainly regarding diet, physical activity and emotional management. It is worth noting the reference to the changes resulting from ageing, considered hindering factors to the compliance with some health guidelines.

...we get to this age, everything tastes good. And sometimes we overdo it a bit and we shouldn't. There are times when I'm sure I'm doing something wrong. I know I should eat less than what I eat because I've put on six Kgs. I shouldn't. But there you go... (P3)

...sometimes I overdo it, at this age one becomes more craving. (P4)

Regarding the third theme, "Importance of a close and trusting relationship with health professionals", which was the most developed by the participants, it is worth mentioning the importance of trust placed in the technical competence of health professionals regarding the support in therapeutic decisions throughout the disease management process.

It's about giving attention, explaining, giving attention... If the person arrives at this stage... giving them a bit of attention. (P2)

I think the most important thing for a nurse is to instruct patients.... Telling the patient what they have, what they don't have, what they should take, educating the patient. For me that's the most important thing. These people need help getting information. Explanation... to take a good look at them is very important. (P3)

The reference to interpersonal aspects and individualised attention was also important, with participants mentioning them as promoters of their sense of security and well-being, especially at a stage of life where they are more susceptible to isolation and loneliness.

If there was a visit or something like that.... Now what I think is that life is becoming more and more isolated ...I think that's even more important than medication. (P2)

DISCUSSION

The increase in the number of older people living with chronic diseases represents a major public health problem. Self-management is viewed as a promising strategy, emphasising the patient's responsibility in the care process. It goes beyond patient education, teaching the patient to actively identify problems associated with the disease, solve them or seek help. It includes dealing with symptoms and disability; monitoring indicators; complex medication management; maintaining adequate levels of nutrition, diet and exercise; adjusting to psychological and social demands, including lifestyle adjustments; and participating effectively in interactions with healthcare[18].

Although all the elderly participating in this study had one or more chronic diseases and symptomatology affecting very important areas of functionality, the self-perceived health and quality of life were described as satisfactory. The results of all subscales and total scale of quality of life were within satisfactory or good parameters, as verified in another study conducted with older people[19]. The scores obtained in the present study were also higher than those observed in the instrument validation study with a sample of community-dwelling older people[16]. Of all the domains, average values were found higher for autonomy, corroborating the positive results found in another study[16]. The way the elderly described their experience in disease management also revealed their feeling of independence and overall functioning in a self-sufficient way.

This might be explained by the fact that some of the most frequent pathologies, such as osteoarticular diseases, are considered to be associated with the ageing process. For this reason, the elderly adapt more easily to their limitations, developing compensatory strategies and gauging their expectations regarding functionality.

Regarding the management of the therapeutic regimen, the results obtained through the treatment adherence scale were high, revealing a good adherence to the medication treatment. Similarly, during the interviews, the older people also reported a high perceived competence in medication management. However, contrary to what the quantitative results suggest, they also described situations in which they changed medication administration and doses or interrupted a treatment prescribed by the physician, replacing it with a more natural alternative.

Although the MAT instrument is widely used in research, both nationally and internationally, the fact that it often produces high scores, even among older people, leads to the hypothesis that a possible ceiling effect may exist. In this sense, the results point to the need for interventions, within the scope of self-management to include this area, namely knowledge and skills required for decision-making regarding medication.

Regarding the non-pharmacological component of the therapeutic regimen, assessed in this study through the lifestyle scale, but also explored in the interviews, again, results were not totally coincident. In the physical activity domain, the mean scores were lower, in line with other studies' findings[12]. The respondents referred to healthy eating behaviours in their responses to the lifestyle scale. However, difficulties in maintaining this type of behaviour were shared during the interviews,

The data presented differences between quantitative and qualitative data, some results were even contradictory. It should be noticed that, , self-efficacy is an important intermediate outcome since it measures an individual's belief in his/her ability to perform specific tasks; but it does not assess the use of strategies or whether self-management tasks are completed[14]. Thus, it is crucial to explore and build new programmes that help sustain behavioural changes to improve health outcomes and reduce the utilization of health services by people with chronic conditions[11]. Thus, useful strategies should be considered and integrated into participants' daily life routines. Otherwise, positive and sustainable behaviour change will be unlikely to occur[14].

In this sense, the design of the intervention to be developed needs to address areas that are domains commonly identified in self-management programmes, which have also emerged in the present study as relevant for the target population. These domains include living with a chronic condition (disease control and decision-making); adherence to medication; healthy eating and physical activity; stress/anxiety management and relaxation; interpersonal relationships and communication with health professionals.

Within the scope of this study, mainly in its qualitative component, the authors strongly believe that the best methodology to be adopted in the intervention would be working with small groups of eight to 12 older people, using activities that, in addition to fostering the development of the participants' skills and self-efficacy in managing their chronic conditions, will be a privileged space for promoting mutual support. Sessions, where health professionals (nurses and psychologists) act as facilitators will also allow to experience and train communication with professionals. More importantly, it will enable establishing relationships that - as referred by one of the participants – will allow attention and response to individualized needs: "For me, it is the most important thing. These people need help getting information. Explanation... taking a good look at them is very important."

The purpose of implementing the chronic disease self-management programme is to promote the development of self-efficacy and a sense of coherence among the elderly. This will empower the older people to better understanding and better manage their therapeutic regimen and help them perceive a more meaningful life [20].

The study had some limitations, such as the small sample size, which does not allow for the comparison and generalizability of the produced outcomes.

CONCLUSION

This study allowed the identification of the health profile and needs of the elderly regarding the self-management of chronic disease, which was an important contribution to the development of a chronic disease self-management programme, within the scope of the project "PT4Ageing: Personal Trainer for health management of older people".

Although the participants perceived themselves as having good health and quality of life, the results revealed some gaps in the management of their chronic diseases that nurses and other health professionals can help develop and improve, thus promoting better health literacy. Also, major relevant areas to be addressed in the intervention programme to this population emerged from this study, such as living with a chronic condition (disease control and decision-making); medication adherence; healthy diet and physical activity; stress/anxiety management and relaxation; interpersonal relationships and communication with health professionals.

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