

Self-care in chronic diseases. The patient-caregiver dyad in the Albanian reality

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Abstract

Background: Multiple chronic diseases mostly affect people over 65 years old, when age-related changes, complicated by physical, cognitive, and emotional problems accelerate functional decline. This increases the elderly population to a high risk of deterioration of their health condition and predisposes to various chronic diseases.

Objective: Patient self-care and the caregiver's contribution to patient self-care is the main purpose of this study. Observation of the patient to reduce the burden of the disease and obtain better results for their life.

Methods: Is a multicenter transversal study at zero time, the study provides for the administration of a validated questionnaire in the Albanian language and addressed to a sample of 30 patient-caregiver dyads in the Albanian population, using specific tools to evaluate the management of the chronic pathology and the patient's self-care skills and the caregiver care framework.

Results: Patients were mainly male (53%) with an average age of 74 years. The average reported selfcare for maintenance score was 57.63, for monitoring the score

was 55.00 and for management was 59.11. For the caregivers the most prevalent subjects were female (60%) with an average age of 60 years old. The average reported score for the contribution of caregivers at selfcare maintenance was 47.08, at selfcare monitoring was 55.00 and at selfcare management was 59.00.

Discussion: This study seeks to determine self-care maintenance, monitoring, management, and confidence by including sociodemographic and clinical variables to assess care outcomes in dyads in the context of multiple chronic conditions.

Keywords: chronic illness, chronic disease, nursing care, selfcare.

I. Introduction

The elderly population is increasing considerably in the world, including in Albania, and with it also the number of chronic diseases, consequently it is necessary to understand the levels of chronic conditions with which the elderly population lives as well as the complexities it brings in health and functional limitations of it (AGS, 2012; Boyd et al., 2014; Koroukian et al., 2016; Ploeg et al., 2017). Many older people live with multiple chronic conditions (MCC), also known as multimorbidity defined as the presence of two or more chronic medical conditions. These diseases have an impact on the patient, which can be positive or negative. This affects the basis of a patient's daily life and his coexisting conditions. Older adults living with these conditions often rely on the support of informal health professionals to help them manage pathologies in their daily lives, making a positive impact. Elderly care, without the right support, can negatively affect an individual's financial, emotional and psychological well-being, further aggravating their health condition. Currently the needs of the elderly with CD are not sufficiently known, and on their need to have a person count that can follow him and help to take care of himself, in the caregiver, as it is known that health influences their needs. In fact, even the World Health Organization (WHO) considers chronic diseases and multimorbidity as significant challenges for our health systems worldwide (Nolte & McKee, 2008). These long-term chronic conditions interact by causing cumulative effects that are highly individualized and often increase with increasing age (American Geriatric Society, 2012; McPhail, 2016). Multiple chronic conditions (MCCs) have not only increased in the United States in people aged 65 years and older, but also in Europe with a prevalence ranging from 24.7% to 51% (Palladino et al., 2016). Unfortunately, compared to people with a single disease, people with MCC have greater impairment of physical functioning, worse quality of life, and higher hospitalization and mortality rates (Gijssen et al., 2001). Therefore, to reduce the impact of chronic conditions and manage symptoms, patients with MCC perform



daily self-care (Kennedy et al., 2007). Research has shown that self-care and the contribution of a caregiver in chronic diseases can improve health-related quality of life (Cannon et al., 2016) and reduce mortality (He et al., 2017; Ruppert et al., 2016), hospital admissions (Hamar et al., 2015; Zwerink et al., 2014) and costs (Wheeler et al., 2003). In these contexts, the relationship of the persons designated as guardians of these patients is essential. Contributions are typically provided by family members or other unpaid persons (Vellone et al., 2019). However, several factors are known to influence self-care behaviors in individuals with chronic diseases, such as sociodemographic factors (such as age, gender, socioeconomic status, and level of education), clinical characteristics of the patient (e.g., number of conditions, prescribed medications), and care partner burden (De Maria et al., 2019a). Taking care of oneself is therefore an integral aspect of human life and self-care needs become more complex when living with chronic conditions (Freedman & Spillman, 2014; Schoen, Osborn, How, Doty and Peugh, 2009; Wagner, Austin and Von Korff, 1996; Wagner et al., 2005). Therefore, when signs and symptoms occur, people adopt a variety of behaviors to deal with them, which is referred to as self-care management (B. Riegel et al., 2019). Self-care is a “decision-making process put in place by the patient to preserve health and manage chronic disease” (Riegel et al., 2018). Referring to Riegel et al.’s mid-range theory, self-care consists of three dimensions: self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance refers to all those behaviors implemented by the person, for health care and physical stability, also emotionality in influencing the course of the disease, factors that determine the progress and improvement of the patient (for example, ensuring sufficient sleep, taking prescribed medications, stress management, being physically active.); Self-care monitoring aims to recognize any changes in the health of the chronically ill person; Self-care management is the process of assessing signs and symptoms of physical and emotional change that serves to determine any action needed to restore health.

On this study it was considered appropriate to focus attention on the selfcare of the patients, but also on that contribution that comes from his family. (Riegel, B., Westland, H., Iovino, P., Barelds, I., Bruins Slot, J., Stawnychy, M. A., Osokpo, O., Tarbi, E., Trappenburg, J., Vellone, E., Strömberg, A., & Jaarsma, T. (2020).

II. Methods

II.1. Objectives

The objectives of this study are to describe the levels of theoretical self-care behavior implemented by elderly patients over 65 years old who suffer from multiple chronic

diseases. Also determining the levels of the caregiver's contribution to self-care behaviors. The study is concerned with the assessment of outcomes related to self-care behaviors of the elderly patient and outcomes related to the caregiver's contribution to self-care behaviors.

II.2. Study design

The Sodality Albania study is a multicenter transversal study at zero time (as it provides a single moment of data collection which is the time of enrollment, quantitative correlational study. because it measures variables with questionnaires on which score scores are identified). The sample consists of 15 dyads, patient-caregivers each of the dyads was given a questionnaire. This questionnaire was distributed physically in the homes of 30 people, respectively 15 of them patients and 15 caregivers of these people affected by various pathologies. The criteria for patient inclusion in the study correspond to the age of patients who must be over 65 years old and suffering from two or more chronic diseases. The diagnosis determined by the doctor must include at least one disease among DB, COPD, HF. Patients diagnosed with dementia and neoplasia were excluded from the study.

The criteria set for the participation of caregivers in the study are based on their adult age and their care for patients against no payment.

For the study to reach a conclusion with accurate results, applying all sampling points, both patients and caregivers must first give their written consent. Willingness to give consent in a formal and professional manner for the continuation of the study.

II.3. Instruments

For the development and approval of participation, a paper questionnaire was administered to the patient-caregiver dyad, a paper questionnaire which was used to conduct an oral and written interview directed by the person in charge of the study. The questionnaire contains a first part of the list of diseases that the patients are suffering, the reading of the consent, responsible for the study, the advantages of participation and how the information will be disseminated. A main socio-demographic part from which it was possible to detect the personal characteristics of the samples, age, sex, level of education, economic condition, marital status etc. The medical records of the patients were analyzed to confirm the chronic condition and the necessary medications based on the documentation of DM, COPD and HF. Care partners also had to report the years and weekly hours of care and whether someone else close to them contributed to the patient's care and the relationship they had with the caregiver (spouse or other). It is a structured interview where



you can neither introduce nor skip questions, but only stick to those of the questionnaire.

The theory of the study is guided by a medium-range theory of self-care of chronic diseases developed by 3 self-care experts (Riegel B., Stromberg H.) and these are:

Self-Care of Chronic Illness Inventory (SC-CII), a tool developed and validated by Riegel and colleagues in 2018 to measure self-care behaviors in people suffering from all types and numbers of chronic diseases. It consists of several sub-stairs, each of which investigates a specific dimension of self-care: Section A (from item 1 to 8): consisting of 7 items (item no. 7 has been omitted during validation) and investigates Self-Care Maintenance. Section B (item 9–14): consists of 6 items (where the 14 has been omitted during evaluation) and investigates Self-Care Monitoring. Section C (item 15–20): consists of 6 items (but another item is being evaluated) and investigates Self-Care Management. The answer options are presented with a five-point Likert scale with a polarity ranging from a minimum value = 1 (“Never”) to a maximum value = 5 (“Always”). The score is standardized from 0 to 100. Where the score 70 represents the cut-off, above which is an adequate level of self-care. However, it must be noted that there are socio-psychological variables that influence self-care, and these can be perceived stress, social support, mutuality, depression etc., and these are evaluated through scales that have been applied and are:

The Perceived Stress Scale (PSS; Scale for Perceived Stress), it is the most used psychological tool to measure the perception of stress. The items were built to intercept the level at which people who respond to the test find their lives unpredictable, uncontrollable. PSS questions relate to the emotional side and thoughts created in the last month. For each item, pcs and caregivers were asked to indicate how often they felt in a certain way and the PSS scores are obtained by reversing the answers (for example, 0 = 4, 1 = 3, 2 = 2, 3 = 1 and 4 = 0) given to the four positively formulated items (items 4, 5, 7 and 8) and then adding up all the items on the scale. (Cohen, et Williamson).

The Mutuality Scale (MS) is interpreted as a healthy, quality relationship between caregiver and patient. Among the mutuality measurement tools in literature, the Mutuality Scale (MS), developed by Archbold et al. in 1990, (Archbold et al, 1990) is the most widely used. It consists of 15 items grouped into four dimensions: “love and affection”, “shared pleasant activities”, “shared values” and “reciprocity”. In the caregiver, high levels of mutuality are associated with less stress, depression, and burden for a better quality of life and self-perceived health; In patients a high mutuality is able to accelerate healing from the disease, reduce anxiety and depression and improve quality of life. (Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T).

The *Multidimensional scale for Perceived Social Support* (MSPSS) (Zimet et al., 1988) was used to assess perceived social support. Instrument, reliable and valid, consisting of 12 simple and easy-to-administer items in which subjects expressed their degree of agreement on a Likert scale from 1 to 7 points respectively strongly Disagree and strongly Agree. Articulated in three dimensions: perceived support from family, perceived support from friends, perceived support from significant others. (Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K.). The MSPSS allowed us to identify a total score for the subjective assessment of perceived social support adequacy by considering them as separate sources.

Finally the *Patient Health Questionnaire-9 PHQ 9* was used to assess the severity of depression, used for the diagnosis, monitoring and determination of depression severity (Spitzer et al., 1999). The PHQ-9 consists of two questions. With the first we asked the dyad about the presence “in the last two weeks” of the 9 symptoms of depression. Only this question determines the score of the PHQ-9. Each symptom was rated on a 4-point scale: “0” (not at all) to “3” (almost every day). The maximum score of 27. The score of 10 is the optimal cut-off.

Lastly, the management of the pc wondered how they manage the chronic disease, if it is prevalent the patient, or the caregiver or if they are both and how they do it. Below are the results with the various evaluations.

II.4. Data analysis

The data collected was analyzed with the use of Microsoft Excel software. The discrete variables were analyzed by calculating the absolute frequency and of the percentage frequency, for the continuous variables have instead been calculated the mean and the standard deviation.

III. Results

The patients interviewed in the study have the following sociodemographic characteristics: 53% of patients are male, with an age range ranging from 68-88 years, with an average age of 74 years. The patients interviewed receive assistance from their caregivers from a minimum of 1 year to a maximum of 9 years, with a minimum time of 10h to a maximum of 21 h. The years of diagnosis of patients vary from a minimum of 2 years to a maximum of 16 years.

The caregivers interviewed in the study have the following sociodemographic characteristics: 60% of caregivers are female, with an age range ranging from 34 to 80 years, and an average age of 60 years. The role of the caregiver is represented for 40% by the spouse, 26.67% by the grandchildren and 33.33% by others (cousin /



cousin). Caregivers assist the patient from a minimum of 1 year to a maximum of 9, with a minimum of 10 h to a maximum of 21 h. In addition, 40% of caregivers have also a chronic disease.

TABLE 1. Sociodemographic characteristics of patient and caregiver dyads

Variables	Patient	Caregiver
Sex	N %	N %
Male	53%	47%
Female	33%	60%
Age	68-88 years	34-80 years
Middle age	74 years	60 years
Education		
Primary school	67%	27%
Lower secondary school	33%	27%
Upper secondary school	-	40%
Vocational school	-	7%
Marital status		
Married / Cohabiting	100%	93%
Widower		7%
Albanian citizenship		
Albania	100%	100%
Current employment		
Employee		7%
Freelancer		47%
Retired	100%	47%
Economic condition		
High	7%	33%
Middle	93%	67%
Low	-	-
N° of people living		
1 person	100%	80%
2 or more people		20%
Live with the caregiver		
Yes	40%	-
No	60%	-
Patient/caregiver relationship		
Spouse	40%	
Grandchildren	27%	
Other (cousin)	33%	
Presence of secondary persons		
Yes	-	93%
No	-	7%
Years of assistance		From 1 to 9 years
Number of hours of assistance		From 10 a.m. to 9 p.m. 14.6h (average value)
Years diagnosis disease	Between 2 and 16 years old Media:8,64	
Presence of 2 Chronic diseases	80%	
Presence of 3 chronic diseases	13%	
Presence of 4 chronic diseases	7%	

TABLE 2. Patient-Caregiver Self Care Measures

	M	DS	Range (min-max)
SC-CII - Selfcare maintenance	57.62	9.72	42.86-75.00
SC-CII - Selfcare monitoring	55.00	13.36	35.00-75.00
SC-CII - Selfcare management	59.11	8.11	46.67-76.67
CC-SCCII – Contribution of the caregiver at self maintenance	47.08	8.64	34.38-62.50
CC-SCCII - Contribution of the caregiver at self care monitoring	55.00	13.36	35.00-75.00
CC-SCCII - Contribution of the caregiver at self care management	59.00	8.11	46.67-76.67

From the results obtained we note an average level of selfcare maintenance of 57.62 (SD \pm 9.72). The analysis of the data shows that most patients have low levels of selfcare maintenance compared to the cut-point value. The results obtained show a maximum self-care value of 75 and a minimum of 35. The average level of self-care monitoring is 55 (SD \pm 13.36) showing that most patients have selfcare monitoring below the cut-point value. From the analysis of the collected data, it appears that most have a low level of self-care management, and only a small part has a higher level of the cut-off with the average level of self-care management 72.89 (SD \pm 11.93) The latest analysis concerns self-confidence from the data analysis it turns out that more than half have low levels compared to the cut-off value. The average value is (SD \pm 11.93)

The sample reports contribution of the caregiver in the self-care maintenance an average level of 47.08, (SD \pm 8.64). However, they still have low levels, as they refer to the self-care of the patients. The data of the contribution of self-care management has an average level value of 55 (SD \pm 13.36). The data of the contribution of self-care monitoring has a mean level of 59.11 (SD \pm 8.11). Self-care confidence data a mean level 61.83 (SD \pm 11.93)

TABLE 3. Multidimensional Scale for Perceived Social Support (MSPSS)

Perceived Social Support (MSPSS)	M	SD	Range (min-max)
MSPSS- friends	4.77	0.54	4.00-6.00
MSPSS- family	6.17	0.26	6.00-6.75
MSPSS- Other	4.95	0.57	4.00-6.00
MSPSS- perceived social support	5.29	0.28	4.92-5.83

The highest levels in family social support are noted, with an average of 6.17, the highest of all the others. The overall average social support of all items is 5.29. The average value of friend's support is 4.77 (SD \pm 0.54). While the other subjects we have an average of 6.95 (SD \pm 0.57).



TABLE 4. Scale of perceived stress and socio-relational variables of patient's mutuality scale

Perceived stress and socio-relational variables of patient's mutuality scale	M	SD	Range (min-max)
PSS TOT- perceived stress	20.4	3.50	15-25
Medium Mutuality Scale	2.77	0.32	2.33-3.40
PHQ-9 Depression Scale	5.53	2.13	2-10

Most patients have an average stress level that has begun to affect their lives. An average perceived stress value of 20.4 (SD± 3.50) is noted in the table. From the data analyzed in the mutuality scale has been seen that most patients have a good relationship with their caregiver. In fact, there is an average value of 2.77 (SD± 0.32). In Patient Health Questionnaire-9 PHQ 9 we then assessed the severity of depression. 10 is the cut-off. Mean value is 5.53 (SD± 2.13). And finally, as many as 73.33% of patients carry out the management of chronic diseases together.

Discussion

Review of existing literature and data confirmed how the progressive aging of the population is a current and always a phenomenon growing. This consequently determines a parallel increase in the frequency of chronic pathologies, which are found more precisely in the elderly population. Chronic diseases can therefore be defined as a social problem, which affects not only the individual but the whole community in terms of costs for the health service, productivity and quality of life. The importance of self-care was highlighted through the review of the existing literature and the results of studies previously undertaken in the field of individual chronic diseases. A good level of self-care has proven itself in able to reduce mortality and hospitalizations, to increase the capacity to symptom management and improve quality of life.

In general, the selfcare of the patient-caregiver dyad in the context of illnesses chronic multiple appears to be adequate in every dimension of theoretical selfcare. Regarding the patient, the behaviors of self-care maintenance, self are adequate care monitoring and self-care management. Our relatively small sample allows us to obtain limited results in the population but significant enough. During this study there were limits: Sample size, difficulty enlisting and difficulties in consent and difficulties in compilation. The study showed a low level of self-care. This stemmed precisely from a low education and the little information that patients had about it, probably due to a difficulty in accessing many services as most of them live in small towns and others in rural areas. Their economic situation is necessary to live peacefully and

has not influenced the low levels of self-care that much. The perceived stress level was not that high, depression levels were also below the threshold, and not only the patient-care giver ratio was found to be quite good. In Albania there are still no studies that describe the self-care of the patient and the contribution to self-care by the caregiver, that's why we can only make a comparison with other countries in the world. In fact, the literature for 10 years now states that economic conditions have greatly influenced self-care levels, as they were unable to provide for it. The different studies carried out have shown a low level of self-care in the 3 dimensions due to a low level of education, but not only has it been shown that women have lower levels of self-care due to high levels of depression. as well as social isolation. (McGilton, K. S., Vellani, S., Yeung, L., Chishtie, J. (2018).

Conclusions

In conclusion, our study shows levels of self-care maintenance, monitoring and management below the adequacy value. There is also a correlation between socio-demographic information and the patient's self-care behaviors and the contribution of caregiver's self-care. The importance of a dyadic approach is therefore argued. However, further research is needed, as the number of samples examined is quite limited. In this study we note a reciprocity of collaboration between patient and caregivers; the latter being, in our sample, a familiar figure and very close to the patient, even if low levels of contribution compared to normal values are reported. The fundamental objective of chronic care systems is to maintain the sick person at home as much as possible. Especially the treatments at home. Also, another goal of an assistance system for chronicity is the achievement of a good awareness and co-responsibility of person in the process of treating his illness. To get a good degree of empowerment requires that the information provided to the person and to all components of its context (family members, caregivers) from every professional figure involved in the treatment process are unambiguous, simple, understandable, homogeneous, and constantly repeated and reinforced. Also, because at the moment there are still no testimonies of studies of this type in Albania. While all the other studies such as in Italy, Sweden, United States present a fairly high number, and this gives a general but also complete picture of the situation of that country or State.

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