Experiences of caregiving and quality of healthcare amongst caregivers of patients with complex chronic processes: a qualitative study.

Abstract

The aim of this research is to explore and analyze the functional status and experiences of complex patients located at levels 3-4 of the risk pyramid of the chronic care model in primary care, within the hospital system of two regions in Spain. The design was a mixed design (COREQ). The participants were enrolled in programs for chronic complex patients and their caregivers. Sociodemographic variables were gathered, together with the following measures: the Barthel test, the Mini mental test, the Zarit questionnaire, the IEXPAC scale and the Braden scale. A semi-structured interview was conducted individually with patients in order to explore their experiences and narrative on the process of their illness and the support they had received. The sample comprised 206 chronic pluripathological patients, of which 103 were from Cantabria and a further 103 were from Mallorca. The patient profile in both regions was very similar. There was an equal distribution across both sexes and the patients were over 78 years old. They all had a basic (primary) education, an average income and required moderate physical dependence, receiving assistance primarily from their children. The qualitative analysis highlighted patients' awareness of the illness and their concern for the future, noting that, overall, patients were satisfied with the care provided by their caregivers and the health system. We can conclude that is the first multicentric study of these characteristics conducted in Spain, despite it being the country with the second largest ageing population in the world. It is important to test new organizational models with differentiating areas of advanced clinical practice in primary care, whereby both patients and their caregivers can be co-responsible within the care process.

Keywords. Chronic disease; Multiple Chronic Conditions; Nursing; Caregivers; Mixed methods.

Introduction

Spain will have the most aged population in the world by 2040, currently ranked third which means that an acceleration of the population ageing process is taking place (Christensen, Doblhammer, Rau, & Vaupel 2009). These individuals are especially vulnerable and fragile, requiring highly complex care as well as extensive sociosanitary resources (Grover, & Joshi, 2015; Mokraoui, Haggerty, Almirall, & Fortin 2016). Moreover, over recent years, there has been an increased prevalence of older patients with chronic illnesses, complex needs, associated polypharmacy and who are at a high risk of functional and cognitive decline. Consequently, the number of hospital admissions and re-admissions have steadily been on the rise (Kinney, Lemon, Person, Pagoto, & Saczynski 2015) The hospitalization of these patients in non-specialized contexts increases the risk of complications, such as delirium or death (Ruiz, Bottle, Long, & Aylin 2015), with almost 5% of patients causing almost half the number of urgent hospitalizations, many of which are due to re-exacerbations or decompensation of their chronic illnesses (Roberts, Rao, Bennett, Loukine, & Jayaraman 2015; Ruiz et al., 2015). The estimated prevalence is 1.4% among the general population and approximately 5% in those individuals over 64 years of age (Forjaz, Rodriguez-Blazquez, Ayala, Rodriguez-Rodriguez, de Pedro-Cuesta, Garcia-Gutierrez, et al., 2015). Therefore, currently, the care of people with chronic illnesses constitutes a priority in the agenda of all health care systems (Falvo, & Holland 2017).

Furthermore, in recent years, different authors and organizations have introduced a new concept of «chronic patient in situation of complexity» which is determined by the profile of the chronicity (Reddy, Sessums, Gupta, Jin, Day, Finke et al., 2017). The most prevalent differential characteristics of this group include the concurrent presence of several chronic illnesses, the frequent need for urgent hospitalization services with different admission episodes within the same year, the presence of certain illnesses, such as heart insufficiency or COPD, decreased personal autonomy, (temporary or permanent), and polypharmacy (Bayliss, Bonds, E., Boyd, Davis, Finke, Fox, et al., 2014; McPhail 2016). Additional factors also contribute to this situation, such as advanced age, living alone or with limited family support, and suffering frequent falls, among others (Vos, van den Akker, Boesten, Robertson, & Metsemakers 2015).

Past experiences of predictive models have revealed that certain factors, such as a previous history of urgent hospitalizations and comorbidity, may have a considerable impact on the probability of an intensive use of resources which could otherwise probably be avoidable (Kogan, Wilber, & Mosqueda 2016). These models provide elements for the identification of groups of patients that require different approaches (Kanter, Lindsay, Bellows, & Chase 2013).

The model of chronicity in Spain

In Spain, several strategies have been adopted in the treatment of complex chronic patients taken from the general context established by the Ministry of Health via the Strategy to Approach Chronicity in the National Health System (Ferrer, Orozco, Román, Carreras, Gutiérrez, & Nuño 2012). A recent systematic review of the literature on the contribution of nursing with regards caring for chronic adult patients conducted in Spain, concluded that nursing interventions have demonstrated favorable results in terms of effectiveness and patient satisfaction (Mármol López, Miguel Montoya, Montejano Lozoya, Escribano Pérez, Gea Caballero, & Hontangas 2018). However, this same review also stressed the need for further studies to determine the effectiveness of nursing practice in chronicity. One of the main limitations highlighted was the heterogeneity of the strategies for approaching chronicity depending on the specific health system of each autonomous community in Spain (Ferrer et al., 2012).

To our knowledge, no comparative study exists between the various autonomous communities in Spain regarding different strategies for caring for chronicity, with similar aims. However, as noted in the previously cited review and similar studies, comparisons have been made between various approaches and interventions, however these are based on different objectives, which makes it difficult to draw clear conclusions (Mármol López et al., 2018: Minué-Lorenzo, & Fernández-Aguilar 2018; Nuño-Solinis, Rodríguez-Pereira, Piñera-Elorriaga, Zaballa-González, & Bikandi-Irazabal 2013; Nuño, Sauto, & Toro 2012). As suggested by the WHO, comparative studies enable us to find convergence points to design global strategies (WHO 2002; Körner, Bütof, Müller, Zimmermann, Becker, & Bengel 2016).

These differences in the design and implementation of care programs for chronicity are based on different reference models, such as the Chronic Care Model and the Innovative Care for Chronic Conditions of the World Health Organization (WHO 2002). These models are based on a global vision and approach different aspects, namely: models, interventions, patients and caregivers. In Spain, increasing importance is given to self-care, as being one of the most relevant dimensions (González 2014). Self-care of the chronic patient is one of the strategies used to improve the capacity of people with chronic illnesses, and to more effectively satisfy their care needs (Stenberg, Haaland-Øverby, Fredriksen, Westermann, & Kvisvik 2016).

Nonetheless, in Spain there continues to be a lack of studies that cover the patient’s role, not just from the point of view of self-care but rather based on that person’s needs regarding what the interventions provide within the program for chronicity. The studies that exist excise, on the one hand, the patient and their self-care and, on the other hand, the interventions performed by professionals. However, they do not ask patients whether professionals appropriately cover their needs derived from their situation of chronicity (Mármol López et al., 2018; Nuño et al., 2012; Nuño-Solinis, et al., 2012).

Therefore, we decided to perform a comparative study between two regions of Spain, which, despite having different models of care, shared the same health objectives regarding the chronic patient (improving the quality of life, reducing hospital readmissions, and promoting self-care). For this purpose, a mixed approach was used, by describing the sociodemographic characteristics of the analyzed population and, also exploring the views of the primary participants, the chronic patients, regarding their opinion and needs concerning their program of care received. In this manner, the recommendations of the WHO are followed, along with the recent literature, in order to appropriately measure other necessary indicators for comparative studies in the strategic design of efficient programs (Taggart, Williams, Dennis, Newall, Shortus, Zwar, et al., 2012).

Study context

This study took place in the public health context of the Autonomous Community of Cantabria and the Autonomous Community of the Balearic Islands (Spain).

Cantabria

Cantabria is an Autonomous Community located in the north of the Iberian peninsula. In general, this region of Spain has an aged population. In 2017, 33,0776 people of Cantabria had more than two chronic pathologies, of whom 14,304 (4%) were classified as complex chronic patients, and 5,802 (2%) were classified as chronic complex high risk patients. This is due to a specific approach based on a Care Plan for Pluripathological Patients which operates as a predictive model for approaching this healthcare situation (SCS 2017). This care path is based on primary care directed interventions coordinated with specific units within the hospitals of reference.

Balearic Islands

The Strategic Plan of the Regional Health Ministry of Baleares defines a model of care for chronicity (Conselleria de salut 2016). The key objective is that complex and advanced chronic patients should receive care that is productive, decisive, appropriate, efficient and satisfactory at all times and stages of life and with the appropriate intensity. To achieve this objective, a series of themes and characteristics of the care model have been established. The resoluteness of Primary Care has been improved, for example, with new roles being created, such as the introduction of a nurse case manager for chronic complex patients in acute hospitals. In addition, specific units catered to advanced chronic patients have been established at medium-stay hospitals and the population has been stratified according to morbidity and complexity and an activity program has been developed.

The main aim of the present study was to explore and describe the experience, level of autonomy and the burden experienced by the main caregivers of chronic complex patients located at levels 3-4 of the risk pyramid of the primary care model of chronicity and hospital continuity of care in two regions of Spain.

Methods

Design

A mixed method was used. The quantitative phase was based on the administration of specific questionnaires to describe the current situation of the chronic complex patient of each region. In the quantitative phase, in-depth semi-structured interviews were conducted.

Population, sample and sampling

Primary care patients were classified as being Chronic Complex Patients of Cantabria and Baleares, over the age of 18 years and without cognitive decline (based on objective assessments). All patients had to have a caregiver of reference who was also included in the study in order to analyze the caregiver burden in the care of the chronic patient.

In this manner, two types of participants were included: patients and their caregivers participated in the quantitative phase of the study while, in the qualitative phase, only patients participated. Due to the difficulties accessing chronic complex patients, non-probabilistic purposive sampling was selected for the descriptive study. In the qualitative phase, this type of sampling is justified for accessing participants based on the key informants who, in this case, were the patients' nurses.

Questionnaires were gathered anonymously from both patients and family members. Participants were previously informed of the study objectives and informed consent was requested in writing, guaranteeing the confidentiality of the information according to the principles of good practice in research and the applicable law.

For the quantitative design, the sample was intentional and theoretical considering the dimensions that could come into play during the discourses, such as age and the degree of dependence.

Variables

In the quantitative phase, we collected sociodemographic variables and health related quality of life measures (EuroQol-5D) based on the Spanish adapted version, (Badia, Roset, Montserrat, Herdman, & Segura 1999), together with Chronic Patient Experience Evaluation (IEXPAC scale, IEMAC 2017 device), the Risk scale for Pressure Ulcers (PU) by Braden (Bergstrom 1987), autonomy in activities of daily living (via the Barthel index, Collin, Wade, Davies, & Horne 1988), caregiver burden (evaluated via the Zarit scale, Martin-Carrasco, Otermin, Pérez-Camo, Pujol, Agüera, Martín et al., 2010), and data on hospitalization (if this took place within the previous 12 months).

In the qualitative phase, a semi-structured interview guide was designed to explore the experience of the chronic complex patient.

The questions were directed at knowing the person's experience with chronic illnesses and the impact on quality of life. The interviews were audiotaped and subsequently transcribed. Interviews were conducted until the point of data saturation.

Procedure

The recruitment of participants was performed on behalf of primary care nurses who were informed and encouraged to select patients labelled as Chronic Complex Patients on behalf of the Primary Care Management. The questionnaires were collected, both for the patients as well as the family members, via an anonymous booklet. The participants were previously informed of the study aims and informed consent was requested in writing, guaranteeing the confidentiality of the information.

Data analysis

For the analysis of quantitative data, a descriptive statistical analysis was performed of each of the study variables. Absolute frequencies and proportions were included for qualitative variables. As measures of central tendency or quantitative variables, the mean and standard deviation were used as dispersion measures, if the distribution of the data fulfilled the requisite of normality. Otherwise, the median was used as a measure of central tendency and the interquartile range, maximum and minimum values were used as dispersion measurements.

In addition, a bilateral contrast was adopted, with a 95% confidence level and 80% power. For the analysis of the possible association among qualitative variables, the Chi-squared test or Fisher's exact test were used and, for the quantitative variables, the Student's t-test was used. For the estimation of parameters, confidence interval parameters were provided. The IBM SPSS Statistics 22 statistical package was used and Excel calculation sheets.

For the qualitative data, an analysis of consent was performed based on the audio transcription of the interviews, their categorization and codification, via the NVivo program.

The association and interpretation processes, together with the extraction of conclusions, consisted of interpreting the transcriptions and their implicit meaning. The criteria used to evaluate the methodological rigor of the study were based on credibility and the ability for audit and transferability, in accordance with Morse and Guba and Lincoln.

Ethical considerations: this research involved data and completely confidential sources, ranging from the personal data of the patients and their caregivers. This study was approved by the Ethics Research Committee of Cantabria (code 2017.049) and the Ethics Research Committee of Islas Baleares (code IB3389/17PI) and was authorized by both health services. The participants received information on the research and signed an informed consent document developed for this study. This study conforms to the Spanish legislation and the principles of the Helsinki Declaration and other international recommendations regarding data protection. There was no conflict of interest among participants and the researchers who performed the study, and the ethical implications of this study were considered at all times.

Results

Results of the descriptive observational study

The sample comprised 206 chronic pluripathological patients, 103 of whom were from Cantabria, and 103 from Mallorca, plus their 206 corresponding caregivers. The patients presented a mean age of 79.1 years (SD= 9.1 range 39-94 years), 52.9% (n=109) were women, 86.8% (n=177) lived in the city, 72.9% (n=129) were home owners, 49% (n=101) had primary studies, 43.6% (n=82) received an income of 500-999 euros/month, 31.3% (n=62) performed, or had performed, an unqualified work activity and 30.7% (n=63) lived with their partner. When comparing both groups, no significant differences were found for the sociodemographic variables (Table 1). Physical dependency was prevalent albeit to a moderate degree and over half of patients did not require any type of aid for their dependency (economic or social resources), with their care being provided by the family, especially their children.

INSERT TABLE 1

Regarding dependency, 69.6% of the sample (n=126) were living with the dependent person in their place of residence. The level of dependency was 83.3% (n=90) physical dependence, whereas 72 % (n=77) presented moderate dependence. Regarding aid, 69% (n=136) did not receive any aid for dependency and 87% (n=167) had no home assistance, although 67.2% (n=121) had a person who provided assistance. This person, in 78% (n=96) of cases was a woman, with a mean age of 57.5 years (SD= 13.9 range 27-86 years), 88.6% (n=109) of caregivers were Spanish, 43.1% (n=53) of times this was a daughter and 31.5 (n=34) of participants had a live-in caregiver (Table 2).

INSERT TABLE 2

The mean scores obtained in all six questionnaires are displayed in Table 3.

INSERT TABLE 3

The results for health-related quality of life (HRQL) assessed using the EuroQol-5D-5L are shown on Table 4.

INSERT TABLE 4

Results of the qualitative study

In total, 19 patient interviews were conducted. These were patients who, in the observational descriptive study, accepted to be interviewed. In total, 12 were from Cantabria and seven from the Balearic Islands. The ages ranged between 35 and 90 years, although most patients were over the age of 75 years, with a total of nine men and 10 women. The mean duration of each interview ranged from between 30 and 45 minutes.

The various discourses were grouped into two large categories regarding exploring the perception of their processes of chronic complex illness: 1) Being aware of the involutions, and 2) Concern for the future.

Being aware of the involutions

People who were in a situation of pluripathology or complex chronicity acknowledged different responses to the loss of autonomy, these ranged from resignation to avoidance, sadness and fear.

Concern emerged related with the loss of autonomy. This was modulated by personality and each person's life story, in addition to any support that the person may have received.

During the interviews, feelings of resignation towards the changes caused by the illness emerged. The most predominant narrative was that the current health status was perceived more as being inherent changes due to old age, rather than to problems derived from chronicity. The patients felt that they had learned to conform to their new situation of chronicity and ageing.

"Yes, I am taking it well… I am accustomed to it, besides, I am not very depressive, so, no… I laugh at it all, with humor, because if not it would kill me… you know what I mean?" Interview 4, male, 72 years old.

For some participants, the illness generated a response of avoidance, in an attempt to avoid facing the situation of chronicity. They played down the diagnosis, treatment and any needs that were not being met. They also simplified the complexity of care required in this situation. In turn, having all the illnesses under control provided them with a sense of control.

"I had to overcome the limitations of the colostomy bag… I didn't break down at any point… when I was so bad I thought a lot about the family, the grandchildren, of course when this happens, a lot comes to mind… but when I saw them, that's it… One day I said "look, if you're like that it's better to die", and my wife said "don't say that word again, because you will be ok, don't worry"" Man, 78 years old.

The participants described feeling sad, mainly because of different reasons related with the loss of autonomy: not being able to continue their leisure activities, feeling like they were a burden to their partner and due to the adaptations necessary due to dependency.

"Sometimes I really feel like crying, I get emotional… I cry because I am no longer self-sufficient!" Woman, 75 years old.

The participants spoke of their concern with the consequences that their loss of autonomy could have on socialization, and entertainment, to be able to face solitude, and maintain a social network, among other issues. In addition, the loss of loved ones, which is more frequent in old age, implicitly led to feelings of loneliness.

"As I am a home lover and since my wife died four years ago, I don't get out… at the time I went out a lot with my wife: for walks, boating, fishing… but now, I can't… I can't jump on a boat… in other words, I have already said my farewell" Man, 80 years old.

The participants also expressed fear regarding how the illness would progress and the consequences of the same. Most expressed dread for their foreseeable increased dependency and the worsening of their health.

"I already told them, the day I die, don't leave me at home, take me to the clinic. First of all, I don't want to die here because my daughter will get scared. Second, there they wash you, dress you and take care of you well… I don't want to be here and have her feeling overwhelmed. That's what I don't want" Woman, 70 years old.

Some participants acknowledged feeling that they had conformed to the changes that came from both the illness and the ageing process. They expressed their acceptance of the new situation as being an adaptive strategy and also as a path towards a feeling of wellbeing. However, these aspects were influenced by personality traits.

"I had to adapt somewhat when I was diagnosed and now my blood sugar is getting complicated, plus my heart and circulation, so they have to take care of me ... it hasn't been so difficult for me to adapt because I´m very easygoing, I understand things and it has gone slowly" Man, 80 years old.

Additionally, some participants felt that their social and family network could manage anything that may arise due to the illness. This feeling contributed to a greater acceptance. If this was not the case, a fear of solitude and its consequences arose.

"My family has always been there, for everything." Woman, 35 years old.

Concern for the future

Concerns for the progression of the chronicity emerged in the discourses. More specifically, some participants expressed fear that they would become more dependent which would lead to requiring further care, more resources and adaptations of the home. In addition, participants voiced their fears of how further functional decline could lead to greater care needs provided by the family. Additionally, patients were apprehensive regarding whether this progression may be accompanied by further suffering or pain.

"Yes my dear, nothing… it's been many years, 90, I am very old. One day I will stretch out my legs and that will be it. I don't ask God not to send me illnesses, to stay in a bed… being a burden to others… if that happens, it's best to die. Interview 2, woman, 90 years old.

The participants expressed concern regarding the limitation of not being able to continue with their everyday life. Concretely, performing their activities of daily living and engaging in leisure pursuits. Others showed an ability to care for themselves, assuming their condition of being chronically ill.

"Having an illness like this, which limits you affects you day to day, it affects some people more than others… I was used to working in the field and now I can't do it, I get tired… but I try to get out every day to have a coffee, I meet up with the other pensioners and we talk" Man, 81 years old.

Another aspect that emerged among participants was concern regarding whether the health and social system would be able to respond to the problems derived from the illness and provide the necessary future care. However, they were unaware of the resources available and the way to access the same. This differed from other participants who already had the formal resources available and adapted to their situation and were also confident that they would be able to use them when needed, as well as knowing where to source the information about these procedures.

"Now I don't need anything, the only thing is that my wife wouldn't be able to take care of me on her own, according to what she would have to do… if I find that one day I can't have a shower on my own, or if I fell, she would not be able to lift me up on her

own, she would have to call someone…. But now we have an appointment with the social worker to ask for help… I hope they give it to me because otherwise…. That's what the nurse manager who came to see me told me to do" Man, 81 years old.

Some patients positively valued the intervention on behalf of the health professionals and their openness. This is particularly the case for those patients requiring care on behalf of the primary care physician or nurse, as these are more commonly available. However, the fragmentation of the different health and social services hampers the ability to resolve problems.

"When my leg got black, my primary care physician came to see me every day, as well as the nurse, I am very happy… they are all available for us when we need them" Man, 81 years old.

Some participants expressed gratitude for the quality of the care received, both at the level of the community and the hospital. Overall, they described being happy with the health service and recognized the doctor and the nurse at the health center as being people of reference in their process of health and illness. Nonetheless, some patients complained of certain treatments, such as the dependence on rehabilitation services, as they were not told about the indications of the same, their duration, benefits, etc. Patients also complained of having multiple appointments.

"The doctors, the nurses (in emergency care), treat you very well. Man, 72 years old.

"I am delighted, delighted. I am thrilled with the doctors, they have always treated me very well. The nurses have also treated me well... yes, I am delighted" Woman, 35 years old.

The small gestures offered by certain health professionals, led to a great sense of satisfaction. For example, receiving recommendations on reading material, receiving a telephone call or an unexpected visit, etc.

"…why? What public health doctor calls you to see how you are? We have been called many times… to see how everything was going" Man, 78 years old.

Discussion

The aim of the present study was to explore and describe the experience, the level of autonomy, and the burden of the main caregiver of chronic complex patients at levels 3-4 of the risk pyramid of the care model for chronicity in Primary Care and the hospital continuum of two regions in Spain.

The profile of the patients included in the study of the chronic complex patient from both regions is very similar: we observed an equal distribution among sexes, with patients aged over 78 years, with primary studies, an average income, and receiving help mainly from their children. Moderate physical dependency was most prevalent and more than half of patients did not receive any type of help for their level of dependence (economic or social resources) with their care being provided on behalf of the family, especially their children. These data are similar to other studies, highlighting pateints of an advanced age, with a similar prevalence among both sexes and with care provided by the children (Calderón-Larrañaga, Vetrano, Onder, Gimeno-Feliu, Coscollar-Santaliestra, Carfí, et al., 2016)

Regarding the level of dependence of these patients, it is important to highlight that the study participants presented a low-to-moderate burden of dependency on behalf of the caregiver. Most dependency aspects were due to mobility issues. The literature on this subject reveals contradictory data, as certain studies highlight the high burden of care and dependency necessary for these types of patients (Forjaz et al., 2015; Hudon, Chouinard, Diadiou, Lambert, & Bouliane 2015) compared to other research, such as ours, which found a moderate dependency and a greater patient autonomy (Kahn et al., 2015; Mokraoui et al., 2016). Nonetheless, there is certain agreement regarding the areas where the quality of life of these patients is most affected, highlighting mobility issues (moderate and severe problems in almost half of patients) and the presence of pain (Sugimoto, Tanioka, Yasuhara, Kurokawa, Sato, Ozawa 2018). It seems reasonable to believe that musculoskeletal problems are highly prevalence and, together with pain, these appear as major disabling factors (Steingrímsdóttir, LandmarkMacfarlane, & Nielsen 2017). Thus, the literature indicates that chronic processes, such as arthrosis, are very prevalent in this age range (Hill, Fatoba, Oke, Hirst, O'Callaghan, Lasserson 2016).

Regarding the patients' experiences of the impact that the process of the illness has on quality of life and functionality, the most prevalent categories were Being Aware of Involutions and Concern for the Future. Different adaptive responses were observed, ranging from resignation, with feelings of dismay and sadness, towards a total acceptance. These narratives also coincide with similar studies which highlight that functional limitations and solitude are feared (highly associated with older age) because of the associated consequences and the way this can affect the quality of life (Årestedt, Benzein, & Persson 2015; Mahon, O'Brien, & O'Conor 2014). The patient narratives on accepting the illness and the loss of autonomy, as well as their feelings of sadness, fear, solitude and feeling like a burden for the family or caregiver, also coincide with similar discourses in older patients with chronic illnesses, as reported in a study by Röing, M., & Sanner (2015) and the study by Ploeg et al., in a Canadian population (Ploeg, Matthew-Maich, Fraser, Dufour, McAiney, Kaasalainen 2017). As stated in previous studies, these cognitive processes may be explained (Obiegło, Uchmanowicz, Wleklik, Jankowska-Polańska, & Kuśmierz 2016; Soundy, Roskell, Elder, Collett, & Dawes 2016) based on coping strategies for stress which suggest attitudes of acceptance of the process of illness as being an adaptive mechanism of the process (Leventhal, & Ian 2012; Matuz, Birbaumer, Hautzinger, & Kübler 2010).

A very striking narrative was the finding that most patients interviewed did not acknowledge having one or more chronic illnesses, not understanding the concept of chronicity or what this meant for them. In these cases, they understood their health process as being an ensemble of processes “due to age” which entailed a functional limitation and dependence on other people. This is also a common finding in other studies (Mokraoui et al., 2016; Obiegło et al., 2016; Ploeg et al., 2017; Vos et al., 2015), as people have acceptance issues because they lack information regarding their chronic illnesses. This situation makes it very difficult for them to assume an active role in their health, which is highly recommendable for any therapeutic approach, albeit difficult to achieve (Mellum, Martsolf, Glazer, Tobias, & Martsolf 2019). A multitude of diverse barriers exist for patients. However, in the present study, the patients did not identify any obstacle related either with accessibility to medical services or the treatment provided by health professionals. Both of which they identified as being satisfactory, which is generally the prevalent opinion regarding the Spanish health system, which is generally considered to be of a high quality (Rico, A., Freire, J. M., & Gérvas 2007; WHO 2016). Therefore, it is necessary to seek other reasons for which patient empowerment is lacking and, the reason patients experience the progression of their illness with resignation and sadness. These sentiments are clearly inappropriate when trying to avoid any potential complications and risk factors related to a poor control of their illnesses (Muth, Blom, Smith, Johnell, Gonzalez-Gonzalez, Nguyen et al., 2018). Thus, it appears that something is clearly lacking in the design and implementation of a strategy for approaching chronic illnesses, as the findings seem to indicate that health care continues to be centered on the illness and guided by a biomedical system focused on the professional and not the patient. Clearly, this situation must be changed, as demonstrated in the positive studies on care for chronic illnesses which are based on person-centered-care (Miles, & Asbridge 2016; Tinetti, Naik, & Dodson 2016).

Regarding the support required for helping people in the management of their chronic illnesses and functional loss, the care provided by the family members was highlighted, with a notable role of the children. This is typical of care provided by families in European cultures, especially in Mediterranean countries, where care of the older population is provided by the nuclear family, especially the children (Van Eenoo, Declercq, Onder, Finne-Soveri, Garms-Homolová, Jónsson et al., 2015). In this study, the patients highlighted positive aspects regarding their children's involvement and concerning the professional support received, mostly acknowledging the positive care received by the primary care and hospital professionals. This is a very common finding in studies conducted in Spain, where the health system is considered one of the best in the world, and where a majority of patients have a very positive opinion of the same (Dueñas, Ojeda, Salazar, Fernández-Palacín, Micó, Torres et al., 2016; Forjaz et al., 2015).

This study has several limitations. First, we only included patients from an urban area. This should be corrected in future research, by including people from rural areas. Another limitation is the lack of a narrative discourse on behalf of the caregivers, who may have helped complement the information provided by patients. Likewise, this should be considered in future studies.

Furthermore, future lines of research should use longitudinal designs to evaluate the long-term impact of the models of care for chronicity. Additionally, it is necessary to measure improvements in the cost-effectiveness of these care models (reduced income, drug consumption, etc.). These research lines are in line with the suggestions by Bengoa, one of the principal authorities in Spain on models of care for patients with chronic illnesses (Bengoa 2013).

Conclusions

Clearly, the present study confirms that, although patients are satisfied with the healthcare they receive, this does not appear to effectively resolve their problems of dependency and functionality. The patients of this study were not aware of their process of illness, which is met with resignation, perpetuating a poor control of the situation and a paternalistic health system. This study portrays the reality of the Autonomous Communities in Spain, as an example of the what may occur in the rest of the country, alerting us of the need to implement realistic and effective measures to put the patient and their families at the center of the system.

The comparative study of both regions enabled us to conclude the following: not all chronic patients are the same and not all patients have equal needs; new organizational models must be implemented differentiating areas of advances in clinical practice in primary care; patients and their caregivers should be co-responsible in the process of care.

Most likely, it is too soon to extract appropriate conclusions, meaning that further studies are clearly required in order to have reliable results, for example, to determine the impact of the morbimortality of these patients. Nonetheless, it appears that these studies, where the patients are allowed to voice their needs and opinion regarding the system, are necessary to design integrated care settings for chronic patients. In Spain, these settings are urgent and preemptory in order to address what is anticipated as being a serious problem in the upcoming years.

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