

## **Empowerment in chronic disease management: a mixed study approach**

### **Capacitação no manejo de doenças crônicas: uma abordagem de estudo misto**

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#### **ABSTRACT**

**Aim:** To explore how empowerment in chronically-ill patients could contribute to their therapeutic regimen management style. To investigate relation between chronic illness impact, therapeutic regimen management style, and the chronic disease intrusiveness's in a person's life. **Methods:** A survey of 271 patients with chronic conditions administered once time with three questionnaires. From this simple (271 patients with Chronic illness.) we did nine interviews with them. **Results:** Regarding the socio demographic variables, age and schooling level reached statistical significance concerning individual empowerment, formally guided, and abandoned scores of the therapeutic regimen management styles. Regarding the predictive model, four multivariable linear regression models were constructed with the overall empowerment level as a dependent variable. The theoretical explanation was identified: "Facilitating decision-making according to each mindset". **Conclusion:** This study confirms the association between individual empowerment, the therapeutic regimen management style and the interference of chronic disease.

**Keywords:** chronic illness, empowerment, mixed methods design, health promotion, evaluation's scales, nursing.

#### **RESUMO**

**Objetivo:** Explorar como o empoderamento em pacientes cronicamente doentes poderia contribuir para seu estilo de gestão do regime terapêutico. Investigar a relação entre o impacto de doenças crônicas, o estilo de gerenciamento do regime terapêutico e a intrusão de doenças crônicas na vida de uma pessoa. **Métodos:** Uma pesquisa de 271 pacientes com doenças crônicas administrada uma vez com três questionários. A partir deste simples (271 pacientes com doenças crônicas.), fizemos nove entrevistas com eles. **Resultados:**

Em relação às variáveis sócio-demográficas, a idade e o nível de escolaridade atingiram significância estatística no que diz respeito ao empoderamento individual, orientado formalmente, e abandonaram escores dos estilos de gestão do regime terapêutico. Com relação ao modelo preditivo, foram construídos quatro modelos de regressão linear multivariável com o nível geral de empoderamento como uma variável dependente. A explicação teórica foi identificada: "Facilitando a tomada de decisões de acordo com cada mentalidade". Conclusão: Este estudo confirma a associação entre o empowerment individual, o estilo de gestão do regime terapêutico e a interferência de doenças crônicas.

**Palavras-chave:** doença crônica, *empowerment*, método de pesquisa mistos, promoção da saúde, escalas de avaliação, enfermagem.

## 1 INTRODUCTION

In July 2014, WHO emphasized the problem of chronicity, identifying it as the main cause of morbidity and mortality in the population<sup>(1)</sup>. Empowerment is a process aimed at increasing the capacity to think critically and act autonomously<sup>(2)</sup>. On the other hand, it can be perceived as a complex goal involving three central concepts: well-being, health and quality of life. In this context, empowerment is a result<sup>(3)</sup>. In the context of self-management of the therapeutic regimen, is a determinant factor to achieving health gains. Promoting empowerment could largely contribute to improving indicators such as the number of hospitalizations, reducing complications or associated morbidities. Thus, contributing to a decrease in the consumption of health services and health care. This study aimed at characterizing the level of individual empowerment of the chronically ill person; identifying the facilitator and inhibitor personal and contextual factors related to the level of individual empowerment; identifying a predictive model of individual empowerment and understand the development of the empowerment process. The process of self-management of chronic disease should promote the development of skills to manage: symptoms, therapy, relationships and emotions, diet, exercise, tobacco, stress reduction, adaptation to work, recognition of exacerbation episodes, interaction with health professionals, the information transmitted and incorporated into their daily lives<sup>(4)</sup>. Therefore, the self-management process involves knowledge and beliefs, self-regulation skills and social facilitation skills to manage chronic conditions or involvement in changing health behaviors<sup>(5)</sup>. The self-management of the therapeutic regimen is a concern of nurses, presupposing helping the person to make informed decisions<sup>(5)</sup>. Although empowering patients for disease self-management is a complex goal that also has a positive effect on the patient's well-being, health and quality of life<sup>(5)</sup>. To achieve the results of client empowerment in the chronic illness it is important to create preconditions for client empowerment for disease self-management<sup>(7)</sup>. The self care is the key to a successful outcome in Chronic's management illness<sup>(8)</sup>. The operationalization of this concept as a result allows understanding and identifying the factors that contribute to empowerment in chronic disease and how they can influence the development of this phenomenon as an outcome. Some authors<sup>(9)</sup> implying a

variety of tools for the evaluation of the construct. Although, not all persons want to get involved in empowerment strategies or feel empowered, it is necessary to classify the dispositional characteristics of person to enable the identification of subgroups of persons who may then receive maximized benefits from health empowerment. The health locus of control, a stable personality trait, and self-efficacy are some factors which can determine empowerment and self-care behaviours<sup>(9)</sup>. Based on social cognitive theory, the concept of self-efficacy ,means that client in their action possessed intentionality, anticipation, self-reactivity and self-reflection, this concept are relating with health locus of control <sup>(10)</sup>. Self-efficacy has been reported to be a mediator between patient empowerment and self-management behaviors <sup>(11)</sup>. In the chronic context, the attitude towards the new demands in self-care, the mastery in the management of the therapeutic regimen and the fluid identity will determine the predominance of the therapeutic regimen management styles <sup>(10)</sup>. The author identifies a set of variables: the locus of control, self-determination, responsibility, coping strategies, knowledge and beliefs that contribute to the characterization of the styles of self-care of the therapeutic regimen <sup>(10)</sup>.

The objective of the study was to characterize Individual Empowerment as a result and identify factors that interfere in this result.

## 2 METHOD

### 2.1 TYPE OF STUDY

A Descriptive mixed methods research was used. The study occurred since July 2014 to February 2015.

### 2.2 POPULATION AND SAMPLE

Local: The study was conducted in Lisbon, the Portugal's capital. An urban place, specifically the geographical area of 17 primary healthcare, where participants were clients. Selected Criteria: Participants were aged over 18 years until 65, who could speak Portuguese, without cognitive or communication problems, and had at least one of this common chronic diseases: cardiovascular disease, cerebrovascular disease, diabetes, chronic respiratory, hypertension, rheumatoid arthritis. The excluded criteria were clients who may have difficulty performing self-care, such as severe disability, dementia, and other untreated medical conditions, and patients with hearing and/or visual impairment. The sample was 271 clients participated in this study.

### 2.3 DATA COLLECTION

The socio demographic information was self-reported by participants, including gender, age, educational level, family income, marital status, smoking behavior's, drink habits, chronic disease type,

and diagnosis duration, exacerbations number, hospitalizations number, treatments, pills number. Empowerment was evaluated by the individual empowerment scale developed for this study by reviewing the literature <sup>(12)</sup>, which includes 28 items for assessing the individual's empowerment. Factorial analysis (main components - Varimax) showed that the 28 items were organized into six factors with a total explained variance of 65.28%. the six dimensions were: Self-perception (items 1-3), Autonomy (items 4-5), and Power (items 6-7), and Mastery (items 8-12), feelings (items 13-19), Participation in health decision-making (items 20-28), and to measure the degree of patient perception of empowerment, items are scored on a 5-point Likert scale ranging from 'strongly disagree' (1 point) to 'strongly agree' (4 points). The total Cronbach's  $\alpha$  0.803 <sup>(13)</sup>. The chronic illness impact was measured using the Illness Intrusiveness Rating scale, which was first developed in 1983 <sup>(14)</sup> and assess the extent to which disease and treatment interfere with people with chronic disease. It includes 13 items. This scale is presented in three dimensions <sup>(12)</sup>: Activities of daily living (items 1,2,3,4,5,6); activities of relationships and intimacy (items: 7,8,9,10); potential for human growth (items: 11,12,13). Each item is measured through a Likert-type concordance scale. The total Cronbach's  $\alpha$  0.920 <sup>(12)</sup>. We measured the Therapeutic regimen management style using an instrument which was developed by Bastos <sup>(10)</sup>. This questioner has three parts. The first part: identity and attitudes towards the disease and the therapeutic regimen, consisting of 45 items. The second part- Perception of behavior towards the Therapeutic Regime, 13 items. This two parts are self-reporting tools. The third part- Characterization of the GRT style in the nurses' perception, 15 items. This questionnaire also allows assessing seven compound variables: internal locus of control, decision-making, self-determination, attitude towards the disease, attitude towards the therapeutic regimen, self-efficacy, and interaction with professionals <sup>(15)</sup>. The therapeutic regimen management styles derive from the variance of response to the flexibility and control required to manage the therapeutic regimen, from which the following styles theoretically emerged: Responsible, formally guided, independent, and abandoned. In this study Cronbach  $\alpha$  0.77. We analyzed data and identified persons with chronic illness with the most level's individual empowerment scale.

## 2.4 DATA ANALYSIS

The statistical analyses were performed using SPSS 22.0. Initially, the data were explored through descriptive statistics using measures of central tendency and dispersion<sup>(16)</sup>. Subsequently, inferential statistics were used to analyze the relationships between variables<sup>(16)</sup>. We used the statistical tests: *One-way Anova*, *T de Student* for independent samples, *Pearson's correlation*. Although not all variables, have a normal distribution, according to the central limit theorem; but the sample has  $n > 30$  subjects, so this means that behave as having a normal distribution. Consequentially we choose using parametric tests. Internal consistency was determined by Cronbach's alpha. To analyze the relationship between the

interference of chronic illness, individual Empowerment, management styles of the therapeutic regimen and socio demographic characteristics, four multivariate linear regression models were constructed. In the qualitative data we did a plan to the interview with some questions. These questions, based on the objectives and framework of the study, were guided around four themes: 1-facilitating factors and barriers of the Empowerment process; 2-people's experience in relation to the process; 3- individual empowering strategies; 4-empowering attitudes and interventions of health professionals. The interviews were audiotaped and transcript.

Validity and reliability/Rigour : Two instruments used were done and validated for Portuguese culture and has well- well-established validity and reliability. The *Cronbach's* alpha for the individual empowerment scale were 0.803 and were used for the first time; The *Cronbach's* alpha for the Therapeutic regimen management style were alpha 0.77 in our study. The Illness Intrusiveness Rating scale were adapted and validated form Portuguese culture and had in our study, the Cronbach's alfa 0,92. The identity of all participants was kept strictly confidential. Furthermore, a professor of statistics was asked to supervise and support the data analysis process. Qualitative data's reliability and rigour was achieved, first: theoretical sampling saturation's was done because we did interviews to rich informants about empowerment; second, data was validated by another investigator.

## 2.5 ETHICAL CONSIDERATIONS

Ethical consent to develop the study in the health units was granted by the ARSLVT (Regional Health Administration) of Lisbon and the Managing Board of the Healthcare Centre Group: Proc.020/CES/INV 10 July 2014. Participants were informed of the study objectives and those willing to participate signed informed consent.

## 3 RESULTS

### 3.1 DESCRIPTIVE ANALYSIS OF PARTICIPANTS

The sample revealed an average age of 56 years (range-18-65), (SD=8.5) . From the 271 participants, 118 were men (43.5%) and 153 (56.5%) women. The majority of the participants (68.6%) were married or cohabiting. Concerning schooling, 35.4% of the participants completed up to the first cycle of basic education, 32.5% up to the third cycle, 21% completed upper secondary education, and 11.1% attained higher education. Hypertension was the most frequently diagnosed chronic disease, corresponding to 80.1% of all reported diseases, either alone or concomitant with other chronic diseases. Administration by oral route was most commonly observed within the pharmacological regime. The daily number of pills varied between 0 and 35 for each participant. Interestingly, although 18 people (6.6%) reported not taking any medication, one person referred to taking 35 pills a day. However, compared to the median (2), 52.8%

of participants were taking up to two pills a day, while 47.2% took more than two. Some participants administered medication through other types of route, such as the subcutaneous route and inhalation route. Hospitalization due to disease complications is one of the most important indicators on disease control and this study showed that 141 (52 %) participants had never been hospitalized for their chronic disease. From the 130 (48%) individuals who reported having had at least one hospitalization, 44.6% referred 1 to 5 hospitalizations, five (1.8%) were hospitalized between 6 and 10 times, and four (1.5%) had more than 10 hospitalizations. However, more than half of the participants, 164 (60.5%) were admitted to the emergency department because of disease-related complications. The majority of respondents (66.4%) reported no complications related to their chronic disease, and 51.3% of the subjects had no other associated diagnosis. The Pearson's correlation coefficient ( $r$ ) was applied to determine the strength and meaning of the association between the sociodemographic variables under study.

Relationships between participant's characteristics, clinical characterization and Individual empowerment, illness disease impact, Therapeutic regimen management style

Concerning participants characteristics and clinical characterization, a relationship between the age of the participants and the educational background ( $r=0.44$ ,  $p<0.001$ ) was found. The results also revealed a negative correlation between age of first diagnosis and the number of admissions to the emergency department ( $r=-0.304$ ,  $p<0.001$ ) and years of illness ( $r=-0.742$ ,  $p<0.001$ ). A positive correlation between the number of hospitalizations and the frequency of attendances at the emergency department due to chronic disease ( $r=0.559$ ,  $p<0.001$ ) was found. This correlation showed the consistency of the results, demonstrating that in situations of disease instability, people attend the emergency department more often and hospitalizations are more likely to occur. Lastly, the findings revealed a positive correlation between the frequency of hospitalizations and the years living with chronic disease ( $r=0.227$ ,  $p=0.009$ ), and a correlation between the frequency of attendances at the emergency department and the years living with chronic disease ( $r=0.348$ ,  $p<0.001$ ). The individual Empowerment scale was characterised by an overall mean of 3.2993,  $SD=0.46516$ , maximum value =4, minimum value =1 and Kurtosis  $SD(0.295)=2.677$ . Through factor analysis the yielded values of  $KMO=0.803$  and the Bartlett sphericity test= $2850.868$  ( $p<0.001$ ) were considered good level. According to the aforementioned in the scale characterization, six factors or dimensions were obtained. This instrument also allowed to identify participants with higher empowerment levels. Since no golden point was reached, the researchers decided that the cohort point would correspond to the fourth quartile, e.g. value set at 3.58. Following this criterion, 25% of the sample ( $n=68$ ) and the remaining 75% ( $n=203$ ) were considered less empowered. When comparing the results between the two groups, more empowered individuals revealed higher indices in decision-making  $t(269)=4.33$ ,  $p<0.001$ ,  $M=2.94$  and  $SD=0.45$ , for self-determination  $t(269)=6.49$ ,  $p<0.001$ ,  $M=3.67$  and  $SD=0.3$ ), for attitude towards the disease  $t(269)=3.11$ ,  $p=0.002$ ,  $M=2.72$  and  $SD=0.38$ , for self-efficacy

$t(269)=3.07$ ,  $p=0.002$ ,  $M=3.60$  and  $SD=0.7$ ) and for the responsible score  $t(269)=7.02$ ,  $p<0.001$ ,  $M=3.75$  and  $SD=0.20$ . Inferential analysis of the sociodemographic variables and therapeutic regimen statistically significant differences for individual empowerment were also found between age groups (T.ANOVA) according to the age of first diagnosis of the disease (Table 1).

Table 1: Inferential analysis of sociodemographic variables and therapeutic regimen for individual empowerment. ACES Lisboa central, Lisboa, Portugal, 2014.

Sociodemographic variables	Individual Empowerment		Therapeutic Regimen Management Styles		Chronic Disease's Interference	
	<b>Age (T. ANOVA)</b> F (270,2)	Identity 4,88	$p<0.009$	Formally Guided Score	$p <0.001$	
	Autonomy and Power 7,94	$p <0.001$	12,45			
<b>Schooling level (T. ANOVA)</b> F (270,2)	Identity 3,02	$p<0.030$	Formally Guided Score 42,46			
	Autonomy And Power 3,90	$p <0.009$				
<b>Diagnosis Time (T. ANOVA)</b> F (270,2)	Identity 3,7	$p<0.012$			Instrumental Activities 3,45	$p <0.017$
					personal growth/ relationships 3,86	$p <0.010$
<b>Marital Satus (T. ANOVA)</b> F (270,2)					Instrumental Activities 3,47	$p <0.017$
					Intimacy 3,40	$p <0.019$
					Personal growth and relationships 3,86	$p <0.026$

Regarding the variables of the therapeutic regimen: the number of diseases, associated diagnosis, hospitalizations, complications, polymedication were found to have statistical significance in the interference of chronic disease; also, with the dimensions of perception, autonomy and power, and the scores of formally guided and abandoned (Table 2).

Table 2: Inferential analysis of therapeutic regimen variables and the chronic disease interference, individual Empowerment, therapeutic regimen management styles ACES Lisboa central, Lisboa, Portugal, 2014.

Therapeutic Regimen variables	Individual Empowerment		Therapeutic Regimen Management Styles		Chronic Disease's Interference	
<b>Chronic disease's number</b> (T. ANOVA) F(270.3)	Perception 8.01	p<0.001	Formally guided Style 3.07	p=0.048	Instrumental activities 16.76	p<0.001
	Autonomy and Power 6.79		Abandoned style 11.07		Intimacy 12.88	
<b>Associated Diagnosis</b> (T. STUDENT) t(269)	Perception 3.67	p<0.038	Abandoned style 3.48	p<0.001	Personal growth and relationships 4.02	p=0.019
	Autonomy and power =2.09				Instrumental activities 6.49	p<0.001
					Intimacy 5.30	
					Personal growth and relationships 2.98	p=0.003
<b>Hospitalizations</b> (T. STUDENT) t(269)	Perception 3.30	p<0.001	Responsible Style 3.64	p<0.001	Instrumental activities 5.49	p<0.001
	Identity 2.34	p=0.020	Abandoned Style 4.09		Intimacy 4.47	
					Personal growth and relationships 2.58	p=0.011
<b>Complications</b> (T. STUDENT) t(269)			Abandoned Style 4.54	p<0.001	Instrumental activities 8.88	p<0.001
					Intimacy 5.66.	
					Personal growth and relationships 3.18	
<b>Polymedication</b> (T. STUDENT) t(269)	Perception 3.94	p<0.001	Formally guided Style 3.60	p<0.001	Instrumental activities 7.34	p<0.001
	Autonomy and Power 2.19	p=0.029			Intimacy 5.39	
					Personal growth and relationships 4.36	

#### Multivariable linear regression model: Empowerment as dependent variable

In the first multivariable linear regression model used to assess the impact of chronic disease interference on empowerment, it was found that: Instrumental activities ( $\beta=-0.11$ ,  $p<0.001$ ,  $IC95\% = [-0.15; -0.06]$ ) and personal growth and relationships ( $\beta=-0.11$ ,  $p <0.001$ ,  $IC95\% = [-0.20]; -0.03]$ ) had a negative and statistically significant impact that suggest a decrease in the level of empowerment, showing higher scores as higher the interference of chronic disease in the identified domains. These variables explain the 16.1% total variation of empowerment. The linear model was well adjusted to the data  $F(270.2)=25.70$ ,



$p < 0.001$ , explaining the linear tendency. The second model studied the impact of the therapeutic regimen management styles on empowerment leading to identifying the scores responsible ( $\beta = 0.55$ ,  $p < 0.001$ ,  $CI_{95\%} CI = [0.44; 0.67]$ ) and abandoned ( $\beta = -0.23$ ,  $p < 0.001$ ,  $CI_{95\%} = [-0.29; -0.17]$ ) as statistically significant variables. According to these results, higher levels of empowerment are related to higher scores for responsible and lower scores for abandoned. These two variables represent 40.3% of explanatory power on empowerment with good linear adjustment  $F(270.2) = 25.70$ ,  $p < 0.001$ . The linear model was well adjusted to the data  $F(270.2) = 90.47$ ,  $p < 0.001$ , explaining the linear tendency. The third model studied the impact of the dimensions of the therapeutic regimen management style on empowerment and found statistically significant results on variables control ( $\beta = 0.24$ ,  $p < 0.001$ ,  $CI_{95\%} CI = [0.10; 0.38]$ ), self-determination ( $\beta = 0.21$ ,  $p < 0.001$ ,  $CI_{95\%} = [0.13; 0.30]$ ), attitude towards the disease ( $\beta = 0.24$ ,  $p < 0.001$ ,  $CI_{95\%} = [0.11; 0.38]$ ), and interaction with professionals ( $\beta = -0.11$ ,  $p = 0.014$ ,  $CI_{95\%} = [-0.17; -0.02]$ ). The five variables with statistically significant results had an explanatory power of 37.7% on empowerment. Linear adjustment of data was considered adequate  $F(270.2) = 90.47$ ,  $p < 0.001$ . The final model was constructed from the variables with statistical significance ( $p < 0.05$ ) from the three previous models, to find the model with the highest predictive capacity on empowerment (Table 3).

Table 3: Predictive model of individual empowerment. ACES Lisboa central, Lisboa, Portugal, 2014

Independent variables	Coefficient analysis			Fit measures		Collinearity diagnoses	
	$\beta_x$ (SE)	p-value (t-test)	95% CI $\beta_x$	$F_{(270,7)}$	$R^2$	Tolerance	VIF
$\beta_0$ (Constant)	1.01 (0.22)	$< 0.001$	(0.58; 1.45)	32.01***	46.0%	-	-
$\beta_1$ Interference in daily life	-0.05 (0.02)	$p = < 0.015$	(-0.09; - 0.01)			0.67	1.49
$\beta_2$ Interference in personal growth and relationships	-0.07 (0.04)	$p = 0.049$	(-0.14; - 0.01)			0.78	1.28
$\beta_3$ Responsible score	0.46 (0.06)	$p < 0.001$	(0.34; 0.58)			0.79	1.27
$\beta_4$ Locus of control	0.16 (0.07)	$p = 0.018$	(0.03; 0.29)			0.35	2.84
$\beta_4$ Attitude towards the disease	0.18 (0.07)	$p = 0.009$	(0.05; 0.31)			0.44	2.29
$\beta_6$ Interaction with professionals	-0.09 (0.04)	$p = 0.018$	(-0.16; - 0.02)			0.62	1.61

The variables with statistically significant results on the final model were the instrumental activities ( $\beta = -0.05$ ,  $p = 0.015$ ,  $CI_{95\%} = [-0.09; -0.01]$ ), personal growth and relationships ( $\beta = -0.07$ ,  $p = 0.049$ ,  $CI_{95\%} = [-0.14; -0.01]$ ), responsible score ( $\beta = 0.46$ ,  $p < 0.001$ ,  $CI_{95\%} = [0.34; 0.58]$ ), control ( $\beta = 0.16$ ,  $p = 0.018$ ,  $CI_{95\%} = [0.03; 0.29]$ ), attitude towards the disease ( $\beta = 0.18$ ,  $p = 0.009$ ,  $CI_{95\%} = [0.05; 0.31]$ ) and interaction with professionals ( $\beta = -0.09$ ,  $p = 0.018$ ,  $CI_{95\%} = [-0.16; -0.02]$ ). The explained variance percentage of

variables included in the final model was 46.0%. Linear adjustment of data was considered adequate  $F(270.7)=32.01, p<0.001$ . Thus, a greater interference of the disease in the instrumental activities and personal growth and relationships, and the interaction with professionals have a negative impact on empowerment, consequently decreasing its levels. On the other hand, higher levels of the therapeutic regimen management style on the responsible, control, and favorable attitude towards the disease types promote the increase of empowerment.

### 3.2 QUALITATIVE ANALYSIS

The qualitative study sampling included nine participants selected from the 271 individuals according to their level of empowerment. A total of 68 people were identified with a high level of empowerment corresponding to 25% of the sample, above 3.58. In the second phase of the study, the theoretical explanation emerged from the interviews' analysis: "**Facilitating decision-making according to each mindset**", including the following three processes/categories or axes, this analysis was based in ground theory approach, and namely: *Being aware of the need to change*; *Perceiving the ability to change*; *Deciding on change*. Being aware of the need to change is the first stage which was characterized by the following indicators: Pre-awareness; Individual factors; Attitudes (people and health professionals) Empowerment facilitating environment. Awareness is a crucial stage in integrating the therapeutic regimen into the person's identity, so the nurse must facilitate awareness of the need to change in the person with chronic disease. It is crucial to promote the reflection about beliefs, values, fears and decisions associated with the disease, and, most importantly, understanding if the person feels capable of changing, and providing all the necessary tools. The next step is perceiving oneself as being capable of change by understanding personal inner power. This perception depends on a set of conditions explained by the: Personal attributes the therapeutic regimen management style predominantly the responsible type, and Support or help from family and health professionals. According to the aforementioned, "deciding on change" is one of the important steps, meaning that the person will have to become aware of the need for change, then perceive oneself as capable of change and ultimately decide to change. This stage is characterized by the integration of the therapeutic regimen and the development of a fluid and solid identity. These three sub-processes happen when the chronically ill person is confronted with the diagnosis, a crucial moment for the nurse to intervene as a facilitator in the decision-making processes in a holistic and tailored approach. The person's awareness of chronic disease is the main factor for change to take place.

## 4 DISCUSSION

The analysis of the correlations between the variables showed that as age progresses, the schooling decreases. This is an important finding because according to international results and the report Health

Literacy in Portugal EU <sup>(17-18)</sup> there is an association between schooling and health literacy: the higher the schooling, the higher the level of health literacy. Also, according to the same report, in Portugal, more than 60% of respondents with higher education have excellent or sufficient literacy levels; in turn, more than 60% of respondents with low schooling have problematic or even inadequate health literacy levels. The literacy level also tends to decrease with age <sup>(17)</sup>. The age of the study participants varied from 18 to 65 years, and older people had fewer years of schooling than younger people, with some exceptions. It was also found that schooling was positively associated with mastery, autonomy and power and, negatively associated with the score formally guided and abandoned. Thus, people with more years of schooling, at the graduate level, for example, have higher levels of mastery, autonomy and power than people with the first cycle of basic education or less, and secondary education, respectively. According to the authors, people with more years of schooling show greater responsibility, and lower formally guided and abandoned scores <sup>(19)</sup>. In addition, knowledge about the disease and management of the therapeutic regimen is commonly found to be associated with schooling <sup>(20)</sup>. Also, in a study by with the elderly population, literacy was found to be associated with schooling, showing statistically significant results <sup>(21)</sup>. This study also showed that the therapeutic regimen management style formally guided exhibited higher results for people aged 61-65 years. The youngest people, aged 18-50 years scored higher for autonomy and power than those aged 51 years or more. However, identity revealed that people aged 61 years scored higher than the youngest participants. Interestingly, this result seems to infer that empowerment is influenced by schooling and the experience from living with chronic disease. Similar to other studies <sup>(10-16)</sup>, this study findings also revealed a statistically significant association between schooling and therapeutic management styles, but this may not be a necessary condition. Despite having lower schooling than younger people, older people showed higher levels in the identity dimension. Identity is a concept built through our lifespan personal experiences. However, reflected previous experiences, learning and overcome stages of inner growth, e.g. "going through development crises" or transitions <sup>(22)</sup>, and a wealthy approach, provide the human being with internal resources mobilized during the different crises throughout the lifespan. Lived experiences enable understanding of how each individual reacts to illness condition, and the literature has been stressing the importance of nurses' accessing clients' experiences <sup>(22)</sup>. The household variable, together with the marital status and either cohabiting or not, also impacts chronic disease, revealing higher scores for people living in hostels or shelters, compared to people who reported living with relatives or friends <sup>(23)</sup>. According to the author, people who perceive better social support also showed higher empowerment. Those who perceive good emotional, informative and instrumental support revealed higher empowerment. We can infer a positive association between social support and empowerment, implying that users with better social support have higher empowerment. Also, social isolation and poverty are factors associated with a high impact of chronic disease and a decrease in the level of empowerment. According to Bastos : "poverty is

the common denominator to all participants with abandoned therapeutic regimen management style, and this group includes extremely impoverished people (...) users of community social services.” (10 p. 269). It was also found that the higher the complexity of the therapeutic regimen, the higher the interference of chronic disease making more difficult to manage crises, decreased empowerment and a greater need to reach out to the emergency department, hospitalizations and thus the predominance of the abandoned style. The variable time living with the disease influences the score for the therapeutic regimen management style predominantly independent, and people living with chronic disease for more than 10 years scored higher for this style. Although people with this therapeutic regimen management style may present a false self-efficacy, they have a strong component of independence and consequently a strong orientation towards self-care, so they are able to find ways of solving the problems and overcome limitations <sup>(10)</sup>. It was also found that the higher the concomitant diseases, the greater the level of interference in the person's life, the lower the overall empowerment and higher scores in the management styles formally guided and abandoned. These study results showed that in the context of primary health care, the interaction with health professional's decreases empowerment, which may indicate that the model of care used by health professionals in the context of chronic disease, is not a promoter of empowerment, being perceived as something that hinders development. The theoretical explanation of the process "facilitating decision-making according to each mindset" means that the intentionality of therapeutic nursing interventions is to support and promote empowerment, autonomy and accountability according to people's individuality. Each human being has his/her individuality and potential to develop mastery and a fluid identity that will enable acquiring skills to help live with the disease. This process of "facilitating decision-making according to each mindset" is phased, corresponding to steps that have to be resolved for the person to move forward, and these are part of the intentionality of nurses when developing nursing therapies. The nine participants in the qualitative study were characterized by high individual empowerment scores, which also culminated in the association with a therapeutic regimen management style predominantly responsible. People with individual attributes of a responsible profile are characterized by being optimistic, independent and proactive. So, "they reject the miserably condition and seek to overcome the constraints imposed by the illness condition, seeking the necessary information" <sup>(10 p. 260)</sup>. Concerning education and knowledge of health resources, the "knowledge of health resources allows not only their use but also mediates expectations" is also an important aspect. <sup>(10 p. 310)</sup>. We believe that regardless of the style of management of the therapeutic regimen, the nurse's purpose will be to develop skills to help people manage the therapeutic regimen and live with the disease. This means that all human being has this potential. However, depending on the different management styles, tailored nursing therapies are needed "according to each mindset". The way each participant expresses himself/herself may be different, but they are all aware of the need to change, namely by integrating the pharmacological and non-pharmacological therapeutic

regimens into their lives. This corresponds to the preparation for change proposed in the trans-theoretical model of Change<sup>(24)</sup> and awareness of Change<sup>(22)</sup>. The process "facilitating the decision-making according to each mindset" is intentional, stimulating the capacity and potential of each person, the intentionality of the therapies lies in maintaining the sense of self and in building/reformulating a fluid identity. However, these study findings showed that the participants did not attribute a meaning to nurses as a resource or support in the management of the therapeutic regimen at the level of primary health care. Limitations inherent to our design requires caution in the transferability and interpretation of findings to other contexts. The availability of validated tools to assess empowerment requires further cross-cultural studies to validate these tools in another settings.

## 5 CONCLUSION

This study has shown that the higher the score of therapeutic regimen management style - responsible, the higher the empowerment level. This study has also revealed that the therapeutic regimen management style - abandoned or formally guided, means lower empowerment level. The personal and environmental factors contributing to individual empowerment of the chronically ill person are: The individual traits, such as the incidence of inner locus of control, positive attitude towards the disease, and perception of self-efficacy; The prevalence of therapeutic regimen management style - responsible; The literacy level; The social and family support; The low interference of chronic disease in peoples' lives; The low complexity in the management of the therapeutic regimen. The validation of Empowerment as a sensitive result to health care may allow the development of knowledge in the Nursing discipline. However, it will also be crucial to know the nurses' perception of this result, what is the attributed meaning and intention of care, in people with chronic illness in the context of primary health care. This study highlights the need to raise awareness among nurses and other health professionals, towards a new philosophy of care centered on the development of skills that allow and favor individual self-determination and responsibility for their own health project, integrated into the individual life project. It also gives visibility to the special vulnerability of people who perceive the disease to be highly severe and, for whom, professionals have to support decision-making and action. Likewise, people who have a negligent behavior with their health or who have a very formally guided self-management style find it difficult to integrate into a philosophy of empowerment and autonomy. The most relevant result, in our view, is that promoting a sense of individual responsibility and the development of skills - mastery is the right way to implement a philosophy of empowerment and so that it can be evaluated as a result, that is, as an indicator quality of care provided.

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## **CONFLICT OF INTEREST**

“No conflict of interest has been declared by the author(s).

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