Empower Me? Yes, Please, But in My Way. Different Patterns of Experiencing Empowerment in

Patients with Chronic Conditions

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Abstract

Empowerment is a widely used word within the realm of health care. This is especially true in the case of patients living with a chronic illness, who may be active participants and learn to manage their disease, irrespective of their desires or preferences. This paper focuses on the empowering experience of patients with chronic conditions. We have built on earlier research that explains the factors that mediate communication between health care professionals and patients: patient participation, patient impact, meaning, health care professionals' information provision, health care professionals' emotional support, health care professionals' attentive listening, health care professionals' trust and patient collaboration. We propose a new model for detecting types of patients who differ in the way they live their empowering experience. Using survey data from a sample of 181 patients of hemophilia, we found two types of patients: patients with an inner locus of empowerment and patients with an outer locus of empowerment. We conclude by discussing different strategies for fostering the sense of power in each of these types of patients.

Keywords: health care professionals-patients communication, patient empowerment, chronic illness, hemophilia, empowering experience, types of patients

The importance of empowerment in the health care field reflects a change in the model of caregivers and patients' communication towards higher doses of mutual collaboration (Emanuel & Emanuel, 1992). This move can be justified in terms of ethical considerations, cost controlling, health outcomes (Schulz & Nakamoto, 2013) and non-health outcomes (McAllister, Dunn, Payne, Davies & Todd, 2012).

Empowerment can be a conceptually complex idea, with different meanings depending on the people and depending on the context (Rappaport, 1995). In a general sense, empowerment can be defined "as the process by which people gain mastery over their affairs" (Rappaport, 1987, p.122). In health care delivery, according to Funnell et al. (1991, p. 38) "patients are empowered when they have knowledge, skills, attitudes and self-awareness necessary to influence their own behavior and that of others in order to improve the quality of their lives." Asimakopoulou, Gilbert, Newton & Scambler (2012) argued that focusing on the patient is the necessary condition for empowerment, "The foundation upon which 'well informed, active partners in their own care' are built" (p.282). This notion of patients as informed and active participants is particularly relevant in the area of chronic illnesses. Patients with a chronic illness must be involved in their own care (Khazrai et al., 2015). Empowerment is an omnipresent facet of the way that patients live their illness. Previous literature has analyzed different aspects of patient empowerment; however, little is known about the empowerment experience *per se*. To fill this gap, in this paper, we analyze the empowerment experience of patients with chronic illnesses.

Different Approaches to Empowerment

One of the main difficulties for defining the empowerment approach in the healthcare field is the confusion about whether empowerment is a process or an outcome (Khazrai et al., 2015). The empowerment theory recognizes two possible perspectives in the analysis of empowerment (Auh, Menguc & Jung, 2014): a macro perspective that considers empowerment as a process and a micro perspective that attends to the outcomes of that process. Of those two streams of research, the one specifically related with the empowerment experience is the micro perspective, also known as psychological empowerment.

The micro perspective of empowerment has been used in the health care field both in terms of patients' preferences and patients' perceptions. There are different ways of measuring patients' preferences for being empowered, such as the Health Opinion Survey (Krantz, Baum & Wideman, 1980) and the Autonomy Preference Index (Ende, Kazis, Ash & Moskowitz, 1989). Departing from these previous instruments, Flynn, Smith & Vanness (2006) developed their own scale for measuring preferences in participation, differentiating between four preference types: deliberative autonomists, non-deliberative autonomists, deliberative delegators and non-deliberative delegators. This approach shows that patients' preferences are characterized by higher levels of heterogeneity. Thompson (2007) determined that this diversity of patients´ preferences is the result of variables such as the type and seriousness of illness, the degree of trust in the professionals and the characteristics of the individuals themselves.

In spite of its usefulness, there are various downsides associated with the use of patients' preferences as a measure of psychological empowerment. Thus, it is not possible to specify their

antecedents (Flynn et al., 2006) and there is a mismatch between stated preferences and actual behavior (Ford, Schofield & Hope, 2003). Moreover, participation is not the result of a preference but an inescapable task in the case of chronic patients. That is why, instead of considering patients' preferences, we analyze patients' perceptions about their empowerment experience. Those perceptions sculpt feelings and emotions that greatly influence the patients' quality of life (Cassis, Querol, Forsyth & Iorio, 2012).

Towards a Model of Empowering Experience

Different patients can have different empowerment self-perceptions within the continuum between compliance and autonomy. An immediate question is how to guide patients along the empowerment path. According to the literature previously mentioned, there are three points that should be taken into account when accompanying the patient through this process: (1) in the case of chronic illness, patients cannot bargain with the responsibility over their treatments; (2) patients can control their treatment, but they do not necessarily control their state of health; (3) illness is an experience of an extreme subjective nature; the empowerment experience should not be viewed under the lens of rationality and objectivity but rather as a response with high levels of irrationality and emotion.

The basic idea behind our approach is that patients' empowerment self-perceptions can be expressed as the result of different tools related to the communication between patients and physicians. In formulating our proposal, we consider a mixture regression model that allows us to identify underlying types of patients who differ in how various facets of the patients/doctor

communication affect their empowerment self-perceptions. Previous applications of mixture models include the seminal works of Heckman and Singer (1984) and Wedel, DeSarbo, Bult and Ramaswamy (1993). In the specific context of health, mixture regression models have also been previously used since the contribution by Deb and Trivedi (2002). The main advantages of mixture regression models are that they allow us to address unobserved heterogeneity and generate unbiased estimates of the parameters.

If we assume a number of clusters *C,* we can specify a regression model within each cluster through the expected value of *Y*, given segment *c,* in the following way:

$$E\text{-}Y_i \backslash c = a_c + b_{1c}X_{1i} + b_{2c}X_{2i} + \cdots + b_{nc}X_{ni}$$

where *Y* is the empowerment self-perception and *X* are the different traits of the patient/health care professionals' communication. Taking into account previous literature in the field, eight dimensions of patient/health care professionals' communication have been considered:

Patient participation (PP). The extent to which patients follow health care professionals' advice.

Patient impact (PI). The patients' active orientation toward influencing others with the same illness.

Meaning (M). Patients' perceptions about the extent to which they feel the consequences of their illness.

Health care professionals' information provision (HCP I). The health care professionals are perceived to facilitate relevant information when interacting with the patients.

Health care professionals' emotional support (HCP ES). The health care professionals are perceived to thoughtfully care for patients, allowing them to share their thoughts and feelings.

Health care professionals' attentive listening (HCP AL). The health care professionals are perceived to proactively require information from the patients.

Health care professionals' trust (HCP T). Patients' expectations regarding the medical care process and feelings of confidence in the health care professionals' ability to meet those expectations.

Patients' collaboration (PC). The extent to which patients engage in shared decision-making.

Method

We empirically tested our model using survey data of a sample of patients with hemophilia. Diverse organizations, such as the World Federation of Hemophilia, have supported the importance of empowerment in the specific context of this illness (Correa, 2009). The interest in analyzing the empowerment experience in this population rests on the following reasons: (1) hemophilia is a chronic congenital illness; (2) patients must necessarily be involved in the control of their illness (therapy administration, report of symptoms and physical status); (3) hemophilia is considered under the category of rare illness, so an appropriate identification of the people affected by this illness is possible; (4) hemophilia requires high doses of interaction between patients and health care professionals to adapt the treatment along the illness cycle; (5) hemophilia involves high medical costs that can be contained through appropriate disease management (Johnson & Zhuo, 2011; Gill et al., 1989).

The study population was composed of patients of any age diagnosed with hemophilia A or hemophilia B, with or without inhibitors, and with regular replacement treatment for hemophilia in Spain. The key informant for this study was the patient. Parents responded on behalf of their affected children in the case of patients aged under 18. Only one subject per household was allowed to participate.

A preliminary version of the survey was pretested. To assure the content validity of the measures, all items were discussed with four health care professionals specialized in hemophilia treatment. This version of the survey was reviewed by two health care professionals and seven researchers. To assess the validity of the measures, we pre-tested the resultant survey with a pilot sample of 16 patients with hemophilia. This pre-test suggested some minor changes in the wording of some questions. Table 1 presents the final version of the items used in the survey[1] to capture the different dimensions of the patient/health care professionals' communication as well as their respective original sources and also provides measurement reliabilities and descriptive statistics for each dimension.[2]

INSERT TABLE 1 ABOUT HERE

The final sample was recruited with the help of the Spanish Federation of Hemophilia (SFH). The SFH (http://fedhemo.com) integrates all of the regional hemophilia associations

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[1] The complete survey is available from the corresponding author.

[2] Confirmatory factor analysis (using EQS 6.2.) was employed to evaluate the psychometric properties of the measurement scales used. The measurement model fits the data well. Furthermore, tests provide evidence of reliability, convergent validity and discriminant validity.

throughout the Spanish territory and includes 4,707 patients, including patients with hemophilia A, patients with hemophilia B, patients with von Willebrand, patients with other bleeding disorders and carriers of the disease, as well as patients' family. The SFH, mainly through e-mail, telephone and web pages, encouraged their members to participate and sent them a link to a web page that contained our survey. The data collection lasted four months (from April to August 2014).

A total of 181 usable questionnaires were obtained, which, taking into account the approximate number of patients with hemophilia A and hemophilia B, represents a survey response rate of 16.5 %, which can be considered acceptable in accordance with previous studies in the field (Ouschan, Sweeney & Johnson, 2006).

The model was estimated using maximum likelihood estimation in GLIMMIX 3.0. Because the main purpose of the model was to determine groups of patients, we repeated the same process with models with different numbers of clusters; the result was that the best fitting model —the one with the lowest value of BIC statistics ($BIC_{one-cluster} = 338.1$; $BIC_{two-cluster} = 337.8$; $BIC_{three-cluster} = 363.8$)— was the two-cluster model.

Results

The majority of the respondents (61 %) receive their pharmacological treatment very frequently (every week), 13 % less frequently (once, twice or three times a month) and 26 % infrequently (every five or more weeks). Table 2 reflects the composition of the patients' sample.

INSERT TABLE 2 ABOUT HERE

This process led to the parameter estimates displayed in Table 3 (the values have been rounded up to improve readability).

INSERT TABLE 3 ABOUT HERE

The implicit consideration of unobserved heterogeneity seems to be appropriate in this case. The two clusters are characterized by quite similar sizes (cluster 1: 55 %, cluster 2: 45 %). As seen in Table 3, three variables are significant in the case of cluster one: patient participation, patient impact and trust in health care professionals. Interestingly, although the parameter estimates of the first and second variables are positive, the parameter estimate is negative in the case of the third variable. In cluster two, there are five significant variables: patient participation, health care professionals' information provision, health care professionals' emotional support, health care professionals' trust and patient collaboration. A first look at the sign of these parameters reveals some noticeable aspects. The coefficient of patient participation, health care professionals' trust and patient collaboration is positive, whereas the coefficient of health care professionals' information provision and health care professionals' emotional support is negative. Therefore, in

this second cluster, only three attributes — namely, patient impact, meaning and health care professionals' attentive listening – seemingly do not have a significant effect.

Taking into account the parameter estimates of the model and the data pattern of each patient, it is possible to calculate the posterior cluster membership probabilities. Each patient is assigned to the cluster for which he/she receives the highest posterior membership probability. A comparison of the profile of the resulting clusters reveals that cluster one is integrated by younger patients (mean age$_{c1}$ = 21.5, mean age$_{c2}$ = 31.4, t=3.8, s.l.=0.00) with a shorter illness experience (mean experience$_{c1}$ = 18.3, mean experience$_{c2}$ = 28.7, t=4.6, s.l.= 0.00). Furthermore, patients in cluster one are healthier. Thus, whereas the percentage of severely ill patients in cluster one is 41.2 %, in cluster two, the percentage of severely ill patients increases to 58.8 % (χ^2=3.8, s.l.=0.05).

Discussion

The findings of our study allow us to identify strategies and tactics that can be used to enhance empowerment self-perceptions in different types of patients. According to our results, two clusters of patients should be considered.

Cluster one is composed of patients whose empowerment self-perceptions are improved through higher levels of illness involvement. In this context, involvement refers to participation, both in their own treatment and in activities of the community of people affected by the same disease. However, the higher their trust in their physicians is, the lower their empowerment self-perceptions will be. This last result might appear very surprising at first glance but can be explained as a consequence of the illness focus of these individuals. This first group of individuals has an

inner locus of empowerment. They consider that their self-ability to manage their illness is driven by themselves. Their own actions —directed towards themselves or towards other people with the same disease— are the forces that improve their empowerment self-perceptions. On the contrary, trust in physicians could be interpreted as a way of transferring the control to a third party.

Conversely, individuals in cluster two are conscious of the importance of their involvement in their own illness but do not try to have an impact over other patients. Their trust in health care professionals and their collaboration with them also improve their empowerment self-perceptions. However, health care professionals' information provision and health care professionals' emotional support have a negative influence over their empowerment self-perceptions. The patients in this second cluster have an outer locus of empowerment. They exhibit a profile of the type, "Ok, I trust you and I collaborate with you, so I am ready to deal with that but I do not want to know any more about this and do not try to be condescending with me" [3].

The distinction between inner vs. outer locus of empowerment can be very relevant. First, it indicates that a climate of trust between patients and physicians only has a positive effect over empowerment self-perceptions for patients with an outer locus of empowerment. According to our research, the profile of this type of patients is characterized by older patients with longer experience with the illness and severe medical conditions. However, there is another type of patient—younger, with less experience with the illness and better medical conditions—who consider himself or herself as responsible for feeling empowered. In this latter type of patient, trying to foster a trustable climate can be counterproductive in terms of empowerment. However,

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[3] All of the quotation marks included in this section refer to interpretations of the authors.

trying to give patients higher doses of responsibility and increase their opportunities to influence other patients can have a positive effect on their motivational empowerment self-perceptions. Another interesting implication is related to the effect of health care professionals' information and health care professionals' emotional support. In the case of the cluster with an inner locus of empowerment, neither of the features of the patient-physician communication have any effect, whereas in the cluster with an outer locus of empowerment, the features of the patient-physician communication have a negative effect. This aspect is very relevant and deserves special attention. It should be taken into account that in recent times, the physician is not the only way of accessing information related with the illness. Thus, even in the case of patients with an outer locus of control, their attitude is more related to the notion that they have the information but need physicians' trust.

To the best of our knowledge, this is the first study that proposes a typology of patients with chronic illnesses according to their empowerment self-perceptions. We can find a parallelism between our results and those of Aujoulat, Marcolongo, Bonadiman & Deccache, (2008), who differentiated between patients with a chronic illness who try to adjust their illness to them (holding on) and patients with a chronic illness who try to adjust themselves to their illness (letting go). Cluster one and cluster two in our typology have some similarity with the holding on and letting go patients, respectively. Our study, apart from identifying those types of patients, describes how different variables of the health care professional/patient communication differently affect both clusters. Additionally, other previous taxonomies, such as Flynn et al. (2006) and Thompson (2007), were not disease-specific and consider patients' preferred role instead of patients' perceptions about what role the patients are actually performing. Our paper deals with situations

in which patients' involvement in health care is not a matter of preference but rather a necessity. Categories such as non-deliberative delegators in Flynn et al. (2006) or a zero level in patient-desired involvement (Thompson, 2007) are not compatible with a scenario of chronic conditions. This different approach allows us to delve deeper into some of the results of these previous studies, particularly regarding the roles of seriousness of the illness and trust in health care professionals:

Seriousness of the illness. In Flynn et al. (2006), the patients with poor health are those that prefer to delegate important decisions to their physicians. We also found that the patients in the group with outer locus of empowerment are the ones with severe medical conditions. This result stresses the relevance of the seriousness of the illness when dealing with empowerment decisions. It is not only that the worse the health condition, the less the desire of involvement of the patient. Our study shows that the worse the health condition, the less the patient feels that he/she is able to cope with the treatment of his/her illness.

Role of trust in health care professionals. According to Thompson (2007), there is a relationship between trust and demand for involvement. This is coherent with our finding that in the group of patients with an inner locus of empowerment, trust negatively affects empowerment self-perceptions. This suggests an interesting perverse collateral effect of trust in health care professionals. It seems that there is an exchange between trust and desire to participate. This reflects the disjunctive between patient and physician as the main person responsible for the treatment. In the presence of trust, the patient relaxes his/her desire to participate. Our results demonstrate that when we consider patients empowerment self-perceptions, instead of preferences, the negative influence of trust only happens in the group of patients with better health conditions.

In the group of patients with an outer locus of empowerment, trust in health care professionals positively affects empowerment self-perceptions.

As in all research, there are some limitations of this paper that should be taken into account. We only consider psychological empowerment; it would be very interesting to compare the results obtained with those derived from a macro approach of empowerment. It could also be very interesting to compare different approaches of psychological empowerment instead of just dealing with self-perceptions. It could also be very useful to analyze the possible influence of cultural factors in the type of relationships considered as well as how differences in the empowerment experience could be explained by variables related to individual temperament[4]. Finally, we have a snapshot of patients' perceptions: possible changes, however, should be expected in those perceptions throughout the life cycle of the illness.

Overall, our results call for a change in the traditional role of health care professionals, reinforcing the importance of managing the motivational dimension of their jobs to the detriment of the more conventional information provision role.

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[4] The authors would like to thank a reviewer for suggesting this line of research.

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Table 1. Variable definitions and summary statistics

Variable	Definition [source]*	Mean	SD
PP	Patient participation (alpha= 0.8) [Adapted from Ouschan et al. (2006); Seiders et al. (2014)]	4.2	0.6
	1. I follow all the indications of the hematology service		
	2. I am very responsible when following my hemophilia treatment		
	3. I am very organized when following my hemophilia treatment		
PI	Patient impact (alpha= 0.8)[Adapted from Spreitzer (1995); Johnston, Worrel, Di Gangi & Wasko (2013)]	3.2	1.2
	1. I encourage other patients with hemophilia to do things together		
	2. I am very involved in activities in favor of people with hemophilia		
M	Meaning (alpha= 0.9) [Adapted from Spreitzer (1995); Small et al. (2013)]	3.5	1.0
	1. Hemophilia is a limitation in my daily life		
	2. Hemophilia seriously restricts my quality of life		
	3. Hemophilia is very inconvenient		
HCP I	Health care professionals' information provision (alpha= 0.9) [Adapted from Ouschan et al. (2006); Chen et al. (2011); Seiders et al. (2014)]	4.0	0.7
	1. Health care professionals usually solve my doubts		
	2. Health care professionals have given me very useful information about my disease		
	3. Health care professionals help me to improve my skills to deal with my illness		
	4. I have learnt a lot about hemophilia from health care professionals		
HCP ES	Health care professionals' emotional support (alpha= 0.9) [Adapted from Chen et al. (2011)]	3.5	0.9
	1. Health care professionals encouraged me to take care of my illness by myself		

2. Health care professionals encouraged me to do other things apart from administering my factor to improve my hemophilia treatment

3. Health care professionals encouraged me to be more involved in my treatment

4. Health care professionals encouraged me to contact other people with the same illness

5. Health care professionals encouraged me to learn from/teach other people with hemophilia

HCP AL	Health care professionals' attentive listening (alpha= 0.9) [Adapted from Ouschan et al. (2006); Camacho et al. (2014)]	3.8	0.8

1. Health care professionals listen to me very carefully

2. I can easily convey to health care professionals my main worries about hemophilia

3. Health care professionals make me feel very comfortable when talking to them

HCP T	Health care professionals' trust (alpha= 0.9) [Adapted from Lee and Lin (2011); Camacho et al. (2014)]	4.1	0.7

1. I completely trust health care professionals

2. Health care professionals always did what they said they would do

3. I am sure health care professionals carry out whatever medical test is needed for me

4. I am sure health care professionals do all they should do to treat my hemophilia in the proper way

5. I trust in the skills of my health care professionals

PC	Patient collaboration (alpha= 0.8) [Adapted from Ouschan et al. (2006); Zainuddin et al. (2013)]	4.3	0.5

1. I try to help health care professionals

2. I answer in detail health care professionals' questions

3. My cooperation with the health care professionals is very important

4. I try to do my best when cooperating with health care professionals

Measurement model: goodness-of-fit indices

χ^2 S-B (704) = 1423.7 p < 0.000; BBNNFI = 0.8; CFI = 0.8; IFI = 0.8; RMSEA = 0.07

*Responses were measured on a five point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (5).

Table 2. Sample statistics

	Mean (SD)
Age	26.8 (17.9)
Experience with the illness	23.8 (16.2)

Type of residence	%	Level of studies	%
City	58.6	Primary	16.0
Town	29.8	Secondary	30.2
Village	11.6	Graduate-postgraduate	53.8
Family income (euros)	%	Type of hemophilia	%
Less than 1,000	5.1	Hemophilia A	83.4
Between 1,000 and 2,000	40.2	Hemophilia B	16.6
Between 2,000 and 3,000	29.5		
More than 3,000	25.2		
Severity of hemophilia	%	Frequency of the treatment	%
Severe (factor level below 1 %)	65.7	Very frequently (every week)	60.8
Moderate (factor level 1 % to 5 %)	16.6	Less frequently (once, twice or three times a month)	12.7
Mild (factor level above 5 %)	17.7	Infrequently (every five or more weeks)	26.5

Table 3. Parameter estimates

| | Cluster 1 | | | | Cluster 2 | | |
Variable	Estimate	Std. error	t-value		Estimate	Std. error	t-value
PP	0.27	0.09	2.92*		0.27	0.05	4.77*
PI	0.13	0.05	2.32*		0.03	0.02	1.41
M	-0.00	0.06	-0.13		0.01	0.03	0.40
HCP I	0.36	0.20	1.79		-0.23	0.06	-3.38*
HCP ES	-0.00	0.12	-0.05		-0.16	0.04	-3.75*
HCP AL	0.25	0.15	1.65		0.04	0.06	0.77
HCP T	-0.51	0.19	-2.65*		0.33	0.07	4.29*
PC	-0.22	0.14	-1.52		0.27	0.08	3.32*
Intercept	2.97	0.57	5.15		1.84	0.29	6.32
R-squared	0.51						
Log-likelihood	-114.31						
ES	0.47						

*Statistically significant at the 5% level.