

Information needs in patients with chronic diseases. How to avoid noise in the doctor-patient relationship?

Necesidades de información en pacientes con enfermedades crónicas. ¿Cómo evitar el ruido en la relación médico-paciente?

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ABSTRACT

In terms of healthcare, information adequate to the patient's needs usually contributes to a better relationship with health personnel, since both actors can share knowledge and improve their communication. In this research, we conducted a qualitative phenomenological study, analyzing the content of subjective experiences explained by chronic patients recently hospitalized in the city of Vic (Barcelona). Our aim was identifying, from the patient's perspective, what messages and topics were the most important for them in terms of information and in which way they preferred to receive them in order to avoid noise. To do this, we developed a couple of focus groups with patients and their relatives and 15 in-depth interviews with patients admitted to the hospital. Results show that patients evidence their predilection for easily understandable and preferably written information,

while at the level of noise and communication problems, patients criticized an excess of communication exclusively oral and insufficient by doctors, something that often generates stress and makes them feel closer to nurses, who are more accessible and communicative. The results also point to the commitment to the co-creation of information between health professionals and the patients themselves to improve future relationships.

KEYWORDS: chronic diseases; information; doctor-patient relationship; noise.

RESUMEN

En cuestiones de salud, una información adecuada a las necesidades del paciente suele contribuir a una mejor relación con el personal sanitario, en tanto que ambos actores pueden compartir conocimientos y mejorar su comunicación. En esta investigación, hemos realizado un estudio cualitativo fenomenológico, analizando el contenido de experiencias subjetivas explicadas por pacientes crónicos recientemente hospitalizados en la ciudad de Vic (Barcelona), con el objetivo de identificar, desde la perspectiva del paciente, qué mensajes y temáticas son los más importantes para ellos a nivel de información y cómo prefieren que ésta les sea transmitida para evitar el ruido. Para ello, desarrollamos dos *focus groups* con pacientes y familiares y 15 entrevistas en profundidad a pacientes ingresados en el hospital. En los resultados, los pacientes muestran una clara predilección por la información fácilmente entendible y preferiblemente escrita, mientras que a nivel de ruido y problemáticas de comunicación, critican un exceso de comunicación exclusivamente oral e insuficiente por parte de los médicos, algo que les suele generar estrés y les hace sentirse más cercanos a las enfermeras, que resultan más accesibles y comunicativas. Los resultados también apuntan a la apuesta por la co-creación de la información entre profesionales de la salud y los propios pacientes para mejorar futuras relaciones.

PALABRAS CLAVE: enfermedades crónicas; información; relación médico-paciente; ruido.

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1. Introduction

We, as 21st century citizens have a growing need for information, especially when assuming the role of patients. Thanks to Internet, we are increasingly proactive, and better informed in terms of health, a reality that tends to contribute to a better doctor-patient relationship, whereas both actors can share knowledge and improve their communication, facilitating that the face to face meeting becomes more efficient (Lupiáñez-Villanueva, 2011).

For Clarke *et al.* (2015), Internet is one of the more common and preferred sources of information due to its facility of access to information, even though in general patients trust their doctors the most by their clinical experience. In this same line, Marin-Torres *et al.* (2012) understand that Internet does not replace the doctor nor undermines his authority, but instead contributes to change the kind of relationship between both, improving the level of participation of the patient. And not only this, but in individuals younger than 45 years old, it can even produce changes in the perspectives and behaviours in terms of health (*Ibidem*).

In the case of chronic patients, Internet tends to have a positive effect in the acceptance process of the disease as well as management of uncertainty. In addition, the cyberspace allows the patient to look for the experience and reality of others like him and share his own experiences also, thus facilitating the community empowerment among patients.

For Abt Sacks *et al.* (2013), a well-informed patient improves treatment compliance and prescribed programme provided by the doctor and also performs a self-management of his disease in an autonomous and responsible manner, at the same time it avoids risks for the patient in terms of the use of inadequate information and promotes and potentiates an empowerment process on health.

Likewise, Barbero (2006) highlights that a duly informed patient clearly identifies his doctor of reference, is more satisfied about his relationship with said doctor and better understands the explanations about his disease and treatment. In fact, this author states that patients aware of their diagnosis not only do not lose hope, but rather show more confidence about the healthcare they receive.

On his part, García-Izquierdo and Muñoz-Miquel (2015) advocate that a well-informed patient not only will feel with a greater control of the situation –which would alleviate anxiety, especially in the initial stages of the disease–, but also it would show a greater compliance to the therapeutic plan and a greater participation and implication in the whole process.

Likewise, physicians around the world opt for informing the patient in a more measured and adjusted manner, considering the complexities of the human being, cultural differences and trying to balance the difficult relationship between honesty and hope (Núñez Olarte, 2014).

All this, in a context where entities offering healthcare services start up organizational models oriented towards customer services, in short, the patient, focusing their concern on the satisfaction and response towards patients' expectations. Therefore, it is more and more relevant to have instruments available that explore the elements of the communication process and access to information, as well as the subsequent decision-making about health based on the patients' view (Simón *et al.*, 2007).

2. Theoretical Framework

2.1. Characterization of the doctor-patient relationship from the informational framework

The doctor-patient relationship can be defined as a “interpersonal relationship with ethical, philosophical and sociological connotations, of professional type that serves as basis for healthcare management” (Rodríguez Silva, 2006) and can be classified in two ways; a) as a guided cooperation, established with patients who can cooperate in the diagnosis and treatment processes, or b) as a mutual participation that involves the monitoring and compliance of treatment, as well as the discussion of the situations and attitudes about the cause and evolution of the disease (*Ibidem*).

This kind of relationship obliges to talk about the medical profession as such, which for Carvallo (2005) should be based on two equally important facets: 1) a scientific-technical facet, through which the professional understands the behaviour of the human body and its pathologies; and 2) another ethical-humanist facet, where the professional must conceive the patient in his fullness and deepness, and where the character, attitude and professional values of health play a capital role to achieve this. To do so, Lin *et al.* (2017) opt for the training of the healthcare personnel in terms of the early and

appropriate communication so that they can regulate their emotions and establish effective communication abilities.

However, the reality is not always so idealised, and often patients perceive the figure of the doctor as an authority with the cure or health improvement in their hands. Therefore, the fact they are distant, unclear and that they do not solve the patients' doubts is excused, at the same time it is accepted, with certain normality that the relationship with the doctor is not affective at all, but effective instead (Simón *et al.*, 2007). This situation leads to, even though patients are willing to know their pathology process thoroughly, they do not assume it as a right, but rather tend to believe that the fact of offering information and involve them in the decision making process is not a professional obligation, but a personal volunteer attitude of the physician instead.

The review of the literature allows us to observe that the doctor-patient relationship has evolved, not only due to technological innovations in the treatments and medical tests area, but also in the way of interacting before a patient that has more possibilities to delve into his pathology through external information sources (Internet, family, other patients, etc.).

The healthcare professional has transformed the way of approaching the patient, moving from a paternalist-like model, where the doctor decided what was best for a passive patient, to a new paradigm where the patient is more active, autonomous and participates in the decision making process (Carvallo, 2005). In this new reality, Carvallo (2005), based on a previous study of Emmanuel (1999), highlights three models that distinguish for outstanding the autonomous role of the patient. The first of them is the informative model, by which the doctor is understood as an expert technician who offers relevant information to the patient and the latter determines the therapeutic scheme to be used based on his values and principles. The second is the interpretative model, by which the doctor plays an advisory role when informing the patient about his affectation, as well as about the risks and benefits of every intervention, together with the value and opinion of the patient. The last and more desirable would be the deliberative model, where the doctor and patient discuss jointly.

What kind of values actually can and must the patient look for in terms of health? Here the doctor acts as teacher and friend, engaging the patient into a dialogue about what kind of diagnosis-therapeutic action would be best. This is, there is a dialogue of friendship looking the best for the patient. (Carvallo, 2005)

From this deliberative model, we understand the concepts of engagement and dialogue, as facilitators or drivers for a symmetric doctor-patient relationship that looks for the appreciation of the patient as a valid interlocutor prepared for the responsible self-management of this pathology and treatment. In short, we observe that a correct communication of information gains relevance as an essential aspect for the autonomy of the patient and serves as pillar of a more participatory and deliberative doctor-patient relationship, where the protagonism of the professional makes room for a more informed and, subsequently, more satisfied patient.

Ruiz-Azarola and Perestelo-Pérez (2012) consider that to achieve a shared decision making, the selfcare education programmes are quite useful, understood as an essential experience for patient awareness about the possibility of being active participants in their health process, especially for chronic patients. Likewise, these educational programmes positively influence in the increase of patient's confidence about selfcare, the improvements in quality of life and in the psychological wellbeing and the increase of self-esteem and activity (*Ibidem*).

However, Ruiz-Azarola and Perestelo-Pérez (2012) consider that some healthcare professionals struggle to accept the increasing empowerment of patients, since this would involve the loss of power traditionally allocated to the former, who would be reluctant to delegate part of it.

2.2. Noise in communication of information and its effect on patient's participation

The literature reveals that in practice there is a great amount of noises and communicational barriers that enormously hinder the correct convey of information between doctor and patient.

A first evident noise would be the level of literacy of the patient about healthcare issues (Menéndez *et al.*, 2017), namely, that the recipient might not share the communicational code with the sender.

A second noise identified is that the information provided by the doctor is not always complete and tends to focus solely in the treatment scheme. This generates doubts in patients whom, in addition, consider that often do not fully understand the information received (Barca Fernández *et al.*, 2004).

Another recurrent communicational barrier is the lack of time the healthcare personnel can dedicate to convey information to the patient, as well as the fact that the doctor does not invite the patient to express his doubts and concerns freely nor questions whether he has understood the information provided or not (Albahiri *et al.*, 2018, Brandes *et al.*, 2015).

On the other hand, Brandes *et al.* (2015) identify a scarce feeling of legitimacy or right about the patient believes to have about expressing his concerns. In addition, the patient tends to be afraid to ask so to avoid deteriorating the relationship with the professional (*Ibidem*).

In this line, for Leydon *et al.* (2000) there are three essential reasons by which patients do not usually request further information about their health to healthcare professionals: 1) faith about the fact that the doctor is an expert and knows what he is doing; 2) hope, something basic to accept their disease and to avoid information of negative nature; and 3) charity, linked to the acceptance that information should be shared with other patients and, therefore, ends becoming unavoidably limited due to the scarce resources of the system.

On their part, Barca Fernández *et al.* (2004) consider that patients do not tend to consult or formulate questions due to three basic reasons: 1) their passiveness; 2) the blind trust towards the doctor – equivalent to the “faith” identified by Leydon *et al.* (2000)-; and 3) the obstacles in communication – specific medical language, interruptions, lack of empathy-. Therefore, and because there are still few the patients to whom opinion is asked about the diagnosis process, authors consider that we are still far from the model of shared relationship where the information flows in a bidirectional manner, thus allowing the joint decision making between the doctor and the patient.

2.3. Information needs by patients

Today, to identify the needs of information from patients –as well as the needs of their family or relatives (Padilla-Fortunatti *et al.*, 2018)– has turned into an essential requirement for healthcare professionals, considering it has been demonstrated that a correct identification of said needs directly benefits the treatment options available (Kassianos *et al.*, 2016). However, in general patients consider not to feel well-informed, that communication is deficient, and that the protection of their intimacy is improvable (Simón *et al.*, 2007).

Authors like Navarro *et al.* (2010) or Ahamad *et al.* (2018) opt for identifying the individual differences in said needs through a patient-centred care and a multidisciplinary approach. In the same line, Hillebregt *et al.* (2017) advocate that the critical needs for every patient profile must be identified according to their social context, their abilities, their lifestyle, educational level, disease perceptions, personal background, desires and capacities.

In general, Bernad Vallés *et al.* (2016) state that patients require professionals with specialized information, scientific-technical competencies, communicational abilities and enough time to keep a dialogue with them, to know their needs for information and their preferences. In addition, in the case of chronic patients, authors advocate the relevance of meeting their expectations and consider their preferences before designing a treatment, since this not only increases their satisfaction with the relationship, but also improves the effect of said treatment.

More specifically, Bernad Vallés *et al.* (2016) detect that patients manifest a concern for the communicational skills of professionals, at the same time they request intelligible and coordinated information between the different professionals and levels of healthcare. Furthermore, patients request a greater amount of information both about preventive activities as well as the disease, specially from the diagnosis and treatment process, so that it allows them to get involved in their care and decision making.

In this way, the communication with the patient is understood as something else than reporting like conveying objective scientific information, since the human being is complex about his information needs (Núñez Olarte, 2014). Likewise, Gil Deza *et al.* (2014) conclude that, above everything patients value the fact that the healthcare professionals show knowledge, humanity in interaction, as well as honesty and experience.

For García Milán (2009) the clinical information offered to the patient must be real, comprehensible for the recipient and adequate to his personal and social circumstances. While according to Almodóvar *et al.* (2018), patients need more objective, constructive information instead of catastrophic-like information, provided in a progressive manner and adapted to the characteristics of each patient.

On the other hand, Barbero (2006) states that information is actually constructed, it is a process and not punctual moments, and that the key of this process is the level of affective and effective communication achieved. Furthermore, this author considers the valid information as:

- Inclusive, since it considers the sociocultural context, the patient's family and his reality;
- Dynamic and a two-way process;
- Sequential and attentive to the evolution of those playing a role in the communicational process;
- Finalist, since it is considered a medium to achieve the emotional control of the patient, autonomy of decisions, collaboration in treatment and the adaptation to favourable or adverse situations.

Likewise, Barbero (2006) also considers that a deliberative process that really helps to decision making must adapt to the other, his reality, his fears and assume the risk of positioning on this perspective by physicians.

Finally, we observe that some patient categories are especially vulnerable regarding the obtaining and use of healthcare information. Specifically, we are referring to patients of old age, with lower

education levels, with healthcare problems and who are not interested and active about the search of information. For these patient typologies, it is essential that the information available in terms of health is understandable and easily accessible, something that information suppliers must keep in mind (Eriksson-Backa *et al.*, 2012).

3. Goals of the study

Even though we have detected an abundant literature specialized in the communication and information needs of different typologies of patients, we observe that in many of them they opt for middle age profile and mostly with literacy in terms of health. In short, they tend to study an age and education profile that tends to be highly influenced by information on Internet, which is something that, as said earlier, contributes to a greater participation of patients and hence, to a more bidirectional communication with healthcare professionals.

However, in this research we decided to analyse a category of patient especially vulnerable in terms of level of information: an old age profile, of rural environment, with scarce education and with a chronic pathology who requires hospitalization as a consequence of a re-agudization of their primary disease.

In short, we aim to contribute to identify the communicational barriers in terms of level of access and understanding of information of this specific patient category, as well as their main needs of information, with the final goal of linking communication aspects to an improvement of the patient's experience, achieving that the information between doctors and patients is not only conveyed but rather understood and recalled, and valued so to modify attitudes that entail improvement in treatment adherence.

Specifically, the objectives of this paper are: a) to identify, from the patient's perspective, what messages and topics are the most relevant for them in terms of information and, b) how they prefer this information to be conveyed to avoid noise.

4. Methodology

4.1. Study design

This study is part of a wider qualitative research with the aim of improving the patient's experience by intervening on communication in those elements and moments that concern chronic patients the most during their hospital stay. To fulfil this objective, the study has been performed following a qualitative methodology with a phenomenological approach (Palacios-Ceña and Corral Liria, 2010) since it is the most adequate to know the meanings elaborated by the patient from his discourse, as an actor (patient) involved in a specific context and situation (hospitalization) analysing the content of subjective experiences explained by recently hospitalized chronic patients. What distinguishes Phenomenology as a methodology is the comprehension and representation of the experience of the social being in his own context, not only understanding it from his physical and social environment, but instead from the distinctive and particular history of the subject, as well as the perceptions, aspirations and privative and intimate concerns of the individual. For Taylor and Bogdan (1998),

The phenomenologist aims to understand the social phenomena from the perspective of the

actor. He examines the way the actor experiences the world. The reality that matters is what

individuals perceive as relevant (...) the human behaviour, what people say and do, is a result of the way their world is defined.

Then, the use of Phenomenology as methodological perspective is coherent, considering that it studies the experiences lived in first person by the individual. Lived experiences that, in our case, refer to a chronic disease requiring hospitalization. From this perspective, the experience of the patient can be contextualized through the moment the experience occurs, the space it elapses and the interaction with other actors involved in said experience.

4.2. Participants and sample selection

The selection of participants profiles was performed through deliberate theoretical sampling, depending on the type and stage of the disease, and the recruitment was done between April and June 2018. Also, the “snowball” technique was used, by which a person recommends another one interested on participating in the study and who meets inclusion criteria. The participants object of the study were those who, coming from their homes, were admitted in the *Consortio Hospitalario de Vic* (CHV) as a consequence of a basal chronic re-agudization. The chronic diseases object of study were the Chronic Obstructive Pulmonary Disease (COPD) and Chronic Heart Failure. In addition, the Type II Diabetes Mellitus was considering due to its relevance for the hospitalization episode, based on medical criteria. Those patients suffering psychomental aspects hindering the understanding of the conditions of their disease and context were excluded from this study, as well as those undergoing a stage of advanced or severe disease (medically estimated death within a period of 3 months or less and/or under palliative care) and institutionalized patients (patients with severe neurological or mental damage)

The sample was comprised by 30 patients of mostly advanced age (54 to 86 years old), of which 70.8% were men and 91% Caucasian. All of them resided in rural areas located in the surroundings of the city of Vic (Barcelona) and with poor or very scarce knowledge and use of technology. The level of awareness about their pathology or disease is rather low and have different stages of the disease. As an eligibility criterion to participate in the study, the patient should be admitted in the hospital after coming from home or the Emergency Unit, being admitted in the ward as a result of a chronic basal re-agudization.

4.3. Data collection techniques

To gather the data for this study, a social research was actually conducted. In order to widen all the perspectives of the phenomenon, a triangulation was done between researchers, who analysed the data and conclusions obtained. Two focus groups were conducted with patients and family to obtain data. To ensure participation, the focus groups were performed during the monitoring visit of the doctor in the next week the patient was discharged.

In addition, 15 in-depth semi-structured interviews were performed during hospital stay. Considering that the study is focused on the experience of the patient, it is important to mention that the hospital stay is understood as the period of time ranging between the moment the patient is admitted, and the discharge or certification specifying the patient can abandon the hospital is issued by the doctor. Furthermore, 4 co-creation of material meetings were held with 6 patients, 2 doctors, 2 nurses, 1 orderly and 2 employees of the administrative area of the hospital.

After the admission registry, the patients were asked whether they wanted to participate in this study and its content and purpose was explained in detail, prior the signature of the consent form. In the case of focus groups, patients signed the participation consent form before the meeting, which was done after receiving the information related to the study. The focus groups and interviews were conducted between April and June 2018.

Before starting the in-depth interviews and focus groups and in order to facilitate the initial communication and generate an atmosphere of trust, the patients were explained the general objective of the study and the guarantee of anonymity and confidentiality in the handling of their data. They were even offered the opportunity to waive participation at any time during the session without offering further explanation about the reasons. The focus groups lasted 90 minutes each, while in-depth interviews were conducted in 45 minutes, approximately. All contributions provided by patients in the 13 interviews and 2 focus groups were recorded in audio format and, subsequently, transcribed literally.

4.4. Data analysis

The data processing and analysis followed the steps of the inductive qualitative content analysis. Considering that the methodological approach highlights the quality and deepness of data about quantity and, in addition, for this study a sample size was not estimated, but instead we used the Data Saturation principle, completing the fieldwork and data collection when no further relevant or new data appeared whatsoever. Namely, when there is no longer significant information collected versus what was obtained so far.

All the transcribed literal information was reviewed by the researchers, who coded and analysed the data entry in the computerized analysis tool called Atlas tiTM v7.5.13.

A previous and inductive analysis and synthesis of results through the reading and coding of transcripts, allows to perform a thematic content analysis based on the relevant narratives shared by patients and their family, as well as a first approach to an explanatory framework of the empirical data obtained and the topics considered relevant. A second re-reading allowed the supervision and segmentation of data, organizing them into units of meaning where there were included those fragments sharing the same semantic meaning. To do so, the constant comparative method was used, by which two researchers read the transcriptions independently in order to find units of meaning that allow the indexation of the fragments describing similar ideas. The triangulation of data guaranteed the reflexivity and allowed the comparison of said indexation among researchers. Once a consensus was reached, there was the individual coding of all transcriptions. The data obtained from both focus groups and the 15 in-depth interviews were split into two levels of structure of the information obtained:

- Level 1: segmentation and identification of units of meaning in the descriptive categories
- Level 2: construction of a system of topics, including several units of meaning or categories.

The results presented in this work come from a secondary analysis of the empirical material related to the noise and elements that negatively influence in the doctor-patient convey of information.

5. Methodological limitations

There was option for the qualitative methodology since it allows to explore and understand, from the patient's perspective, the way of interpreting these studied phenomena considering the context. Although it grants deepness, its main limitation is being an exploratory study. Regarding future

research lines, we suggest completing the results obtained and exposed in this paper with qualitative methodological approaches that contribute a broader scope and generalization.

6. Results

From the qualitative analysis of the data obtained, there resulted 377 units of analysis, which were grouped into 22 categories and 6 topics. For this study, we will focus solely on the categories that refer to the noises hindering information offered to the patient and the needs of communication expressed by him. Said categories are indicated in the following table:

Table 1. *Frequency of categories and topics.*

Categories and topics	Interviews	Focus Group	Total
Content of information			
Information provided by the doctor	53	16	69
Understanding of information	63	11	74
Lack of information	10	3	13
Information about admission	37	11	48
Professional-patient relationship			
Trust in the professional	5	4	9
Shared decision-making	6	0	6
Professional care	26	11	37
Patient's proactivity			
Family context	6	3	9
Behaviour and attitude	19	7	26

Source: author's own elaboration.

Likewise, on table 2 there is a sample of quotations from participants that illustrate the informative contents obtained.

Table 2. *Verbatim pieces from interviews and focus groups for each category and topic.*

Content of information
Information provided by the doctor
<i>I don't want anything that isn't in written.</i>
<i>The functioning was explained to me in an accurate manner and then went inside and that's it. End of story.</i>
<i>The doctor is not a talkative person really. It is a good doctor, I think, but it is not someone that empathises with you and says 'hey, this is what will happen, this and that...' No. He says instead, 'you have this, you have a very severe state and we must try to stop it'. That's it. He doesn't say anything else and I would like that... they do not tell me anything... I would like that someone could say, even if it is 'look, we cannot do anything, but only provide palliative care and that's it.' But nobody tells me this. I would also like to know.</i>
Understanding of information
<i>That's it, that's what the doctor told me. Surely, he said so, freaking out everybody and that's it. But I keep holding on, it's fine.</i>
<i>But I wonder, because sometimes I think, well, I am not smart enough nor understand properly for any reason. But no, I prefer that things are explained well to me. Or at least that I understand them well (...) Please explain well, that I understand well, yes, that's right.</i>
Lack of information
<i>Because the time goes by... No, no, they do their job and you do not understand her, and you think that girl going up and down, that doctor should do something. And she is already doing so, but you do not understand her.</i>
<i>I don't want to be told a lie; I want them to be honest with me. But I would like that, of course, they physically can't.</i>

Doctor-patient relationship
Trust in professional
<i>Yes, I swear I am thankful about what you did with me today, because I was rather scared and, on the other hand, you were reassuring. And the truth is that 'It is worth it' and that I have really valued you very highly.</i>
<i>You trust (...) the professional completely and say, 'It cannot be you'. But of course, after the second surgery you start to doubt a little bit about everybody. Without mistrusting (...) the professional. eh? Because he tells the truth, at least in my case he did.</i>
<i>Perceptions about what you say, 'it happened to you because it is the doctor you did not like'. Hey, I choose the doctor, I couldn't say anything against him... on the contrary, he is a person I can trust.</i>
Shared decision-making
<i>They go too fast, they don't have time to listen, they don't have time to listen what you want to say. I would like to explain much more things than the doctor requests ...</i>
<i>Sometimes I think that we don't heal properly because the doctor doesn't have time to listen what we think about the disease.</i>
Professional care
<i>In my case, I am only missing something... that they should, I mean, they are very pretty, very kind, but I am missing a point of caring, or support, I don't know ...</i>
<i>It is a little bit of everything, a little bit of everything ... But above all, above all, is about having more time so that you can explain your discomfort or wellbeing, because sometimes it is good to be able to say 'I feel very well, I have gotten better. It is also good to be able to explain the joy, not always the sadness, right?</i>
<i>It is also very nice to be able to explain: 'I feel very well; I have gotten better. And, that relationship was lost, it was lost or it is being lost, regarding that doctor-patient relationship, eh?</i>
<i>There is a psychological part missing here, and missing a lot, because it is not only about the patient... but about the environment itself. Today my wife said that she wanted further explanations and she found, well, that perhaps she was not given enough. Perhaps I am more tolerant, it is not that I am...</i>

Source: authors own elaboration.

From the three categories selected for this paper, the ones that corresponds to “Content of Information” summarizes the feelings and behaviours the patient must cope with in relation to the information provided, and it includes four topics of its own: a) information about admission, b) information provided by the doctor, c) understanding information and d) lack of information.

The patients were asked about whether they received information about the decision and the reason to be admitted in the hospital through the ER unit. All patients manifested they were informed about the admission and the reasons for said hospitalization: “Below (ER) I was well informed that I had an infection and that I needed to stay” [woman, 70 years old]. However, if patients manifest respiratory symptoms they can be confused and, some of them, may have difficulties to recall the information provided: “I do not know whether we talk about it, but I already knew because I felt ill” [man, 83 years old].

Regarding how the information provided by the doctor is assessed, patients coincide in the fact that the doctor is the one who provides the information and diagnosis: “the doctor provided thorough information” [man, 80 years old], while others explained they obtained information at the hospital and not while they were visited in Primary Care: “the doctor told me I had COPD. The GP did not tell me that, that I had COPD, but he urged me to quit smoking” [woman, 54 years old]. In addition, some patients mentioned to look for information on Internet on their own, although not everything they found can be considered as valid nor reliable information: “it is clear, perhaps I look for a lot of information on the Internet on my own (...) besides, I am aware that not everything I find on the web is reliable” [man, 74 years old].

Secondly, the category “Doctor-patient relationship” includes three topics: 1) trust in the professional, 2) shared decision making and 3) professional care. Regarding the first topic, the

responses of patients are unanimous and in all cases they outstand trust as main pillar in the relationship with the doctor: “if you see it this way, I do not understand anything, but you are the expert” [man, 66 years old], “I did what I was told to do and that is all” [man, 77 years old], “I never doubt the professional because he tells the truth, at least in my case he always did so with me” [man, 80 years old]. In addition, patients answered negatively to the question about whether they participated in making those decisions that influenced their wellbeing during the hospital stay: “I would say no” [woman, 69 years old].

The participants described the professional care in terms of what they could witness for themselves, as spectators of what happened around them. At this point, there were several comments describing the frequency of visit of the professional, such as: “the doctor came every day”, being the doctor the only one who explained the situation and, in addition, how the doctor and the nurse interacted in their respective roles: “nurses are the ones to do so, they follow the doctor’s instructions... they do everything and then the doctor comes with results as if he had done the whole process himself” [man, 76 years old].

The third and last category analysed in this study, “Patient proactivity”, includes the topics “family context” and “behaviour and attitude”. Regarding the first topic, the comments of patients were focused on the role of caregivers and, more specifically, in the responsibility about taking medications. In this case, family caregivers said to be often attentive about any change in the name or number of medications, what is their function, preparation and dose. Also, caregivers say to be responsible for the preparation of the dosing and the treatment compliance: “I am responsible for medication. I am, you may watch (the patient), but I administer the medication”; while the patient indicates that “Now, I do not take care of anything, right? Like in the last hospitalization, she (the caregiver) does everything” [woman, 70 years old].

Regarding the behaviours and attitudes, patients did not make many comments, although the support between other patients who have the same disease is unanimous.

In a more general and transversal manner, we also observe that patients show their preference for information that is easily understandable and preferably in written, while that, regarding noise and communication issues, patients tend to criticise the excess of exclusively oral and insufficient communication by doctors, something that tends to generate stress and that makes them feel closer to nurses, who tend to be more accessible and communicative.

7. Discussion and conclusions

In this study we will focus on detecting the needs for information and the noises they evoke in the doctor-patient relationship in the specific context of hospitalized chronic patients of old age and with a low level of technological literacy, therefore, they might differ compared to other studies performed with different patient profiles.

Anyways, we observe several similarities with previous studies. The most relevant is the fact that most patients tend to need a greater level of information that the one received actually, even though, due to different reasons, they do not dare to request it (Albahiri *et al.*, 2018; Barca Fernández *et al.*, 2004; Brandes *et al.*, 2015; Leydon *et al.*, 2000).

We also highlight a clear preference of patients for written information versus oral, results that coincide with those of García-Izquierdo and Muñoz-Miquel (2015), who highlight that the written

information guarantees the patient that the information received is understandable and updated, at the same time it reassures about the suggested treatment.

Regarding who provides the information and how the best way to access to it should be, patients understand that the doctor is the responsible for informing about the health status, in detriment of other sources like Internet. In this sense, our study coincides with the view of Clarke *et al.* (2015) and Marin-Torres *et al.* (2012).

Our study also demonstrates that the time pressure is a key factor that negatively impacts not only access and understanding of information, but also the doctor-patient relationship, as indicated previously by Albahiri *et al.* (2018), Bernad Vallés *et al.* (2016) or Brandes *et al.* (2015), among others.

In addition, it is observed that for patients it is extremely important that doctors can establish a symmetric and bidirectional dialogue with them. They demand to be seen as a valid interlocutor of the process and evidence that, despite their desire of greater participation (Bernad Valles *et al.*, 2016), there predominates a paternalistic doctor-patient model (Carvalho, 2005).

This lack of active participation of the patient results into one of the most harmful noises in the relationship: not to recognize the value of the patient as human being and, in addition, it adds the loss of respect and authority towards the professional. A reality that leads, for instance, for patients to openly manifest having a greater and better access to nurses than physicians, with whom they build a relationship of trust and openness that allows them to comment topics that go beyond their disease. In this sense, we identify that nurses are those professionals in whom patients mostly trust their concerns to.

Likewise, we highlight that patients consider especially important to establish a private atmosphere during visits, trying to minimise all those external noises that could affect it, for instance, by avoiding interruptions, either caused by non-healthcare professionals or by family.

However, like Kassianos *et al.* (2016), we also observe the need to include the closest family in a positive and active way, whereas it is helpful to minimizing uncertainties and noises in the information provided to the patient.

Finally, as a recommendation, we believe it is necessary that the doctor adapts his vocabulary and discourse approach to the context and cultural level of his or her patients. Therefore, it is important to avoid all that kind of excessively technical language that hinders understanding by the patient. This situation entails noise such as doubt, fear and uncertainty for the patient. Without considering the cultural and social context of the patient, the doctor will fall –once more– into those noises that hinder communication understood as a collective and mutual process.

8. Ethical aspects

The study was approved by the Clinical Research Ethics Committee of *Fundación de Osona* on research and healthcare education. The participation was volunteer, and participants were informed verbally and in written about the objectives and contents of the study. The transcriptions of the interviews and focus groups where conducted in an anonymous manner to keep the identity of participants confidential.

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