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## INFORMED CONSENT TRANSLATION AND COMMUNICATION AS A TOOL TO ENSURE ITS COMPREHENSIBILITY

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### Abstract

In the globalization and migration era, the paternalistic model in healthcare is affected by a new direction giving way to patient prominence and, therefore, activation. The diversity of patients in the Spanish medical consultations involves different communicative scenarios in which the medical interpreter and translator plays a crucial role as for example the delivery of documents addressed to the patient in the medical consultation with foreign patients. In this paper, we integrate research in informed consent from readability and comprehensibility. A qualitative and quantitative study on how professional dentists perceive the interpreters' role is carried out. The needs of a sample of native and foreign patients as users are also covered.

### Resumen

En esta era de globalización y migración, el modelo sanitario paternalista se ve afectado por un nuevo rumbo donde el paciente también adquiere protagonismo y, por ende, un papel activo. La diversidad de pacientes que acuden cada día a los centros sanitarios españoles comporta distintos escenarios comunicativos para los que la figura del traductor e intérprete médico ocupa un papel fundamental. Uno de estos escenarios es la entrega de documentos dirigidos a pacientes en la consulta médica con pacientes extranjeros. El presente trabajo revisa las líneas de investigación del consentimiento informado desde la legibilidad y la comprensibilidad. Se presenta un estudio cualitativo y cuantitativo sobre la percepción de los odontólogos profesionales del papel

del intérprete y las necesidades de una muestra de pacientes autóctonos y extranjeros como receptores.

**Keywords:** Informed consent. Interpreters' role. Medical communication. Patient empowerment. Comprehensibility.

**Palabras clave:** Consentimiento informado. Papel del intérprete. Comunicación médico-sanitaria. Empoderamiento del paciente. Comprensibilidad.

## 1. A paradigm shift: from medical paternalism to patient empowerment

During the last few years, we have been witnesses to the beginning of a change in the medical assistance model in the developed western countries due to the increase and access of the ways of knowing as well as the tendency towards the patient training (Epstein *et al.* 2005: 1520; Mayor Serrano 2005: 133; Muñoz Miquel 2014: 172). This change in the relationship between the healthcare professional and the patient involves a necessary creation of well-adjusted materials which include the patient. Indeed, this is where translators, interpreters, mediators and medical writers can contribute and have a wide field of action for adapting the abovementioned materials regarding cultural background, location, sickness and needs, etc. In order to spread specialized knowledge, different translation perspectives have been considered and studied such as heterofunctional translation consisting of the information reformulation so that the target text has a different function from the source text (García Izquierdo & Montalt i Resurrecció 2013: 47).

In most of the documents drafted, the different readers this kind of documents may reach are not taken into account, that is to say, they are addressed to a standard patient. Therefore, if healthcare professionals increasingly join forces in order to personalize medicine (Sánchez Martos 2014: 96-104), why not to personalize communication through written and oral information? Who must begin this process?

## 2. Medical communication and text types

### 2.1. *The importance of the medical translator/writer or interpreter*

In light of the change of the medical attention model, patients want and need greater access to written and oral information in order to adopt a more active role in decision-making. The problems come from the gap in the training related to the communication of professionals who do not have or were not trained for spreading the specialized knowledge, as García Izquierdo & Montalt i Resurrecció (2013) already discussed.

Within the medical interpretation, texts such as informed consent expose the interpreter to the multidisciplinary challenge to achieve an effective communication. Not only is the knowledge of specific terminology in related theme areas required, but its familiarization with the principles, purpose and different ways of presentation of this material, teamwork with healthcare professionals, etc. is also fundamental.

Therefore, it is highly important to try to clarify which role the interpreter takes in the informed consent process. We should remember that we started with a written document which requires oral interaction.

During the last decade, there have been a lot of studies aimed at clarifying and categorizing the interpreter role in the health field. We can highlight/mention models such as the law and impartiality model proposed by Cambridge (2002) or Leanza's (2005) approach to the interpreter role as a communication facilitator or a cultural assimilator and, during the last decade, the *patient navigators'* model proposed by Crezee (2013). This last model highlights the cultural differences that may arise in the consultation and the interpreter is the one who intervenes as cultural liaison like Crezee (2013: 17) expresses:

Even if the interpreter interprets such words appropriately, a culture-specific misunderstanding may arise and the interpreter may need to act as a cultural liaison and resolve the resulting communication breakdown.

## 2.2. *User-oriented communication*

In the healthcare context, proper communication is fundamental and essential even though in some contexts it can be seen undervalued. In the informed consent context, it can, or must, never be undervalued since the receiver obtains information of vital importance like instructions, side effects, procedures, symptoms, available treatments, risks, benefits, etc. Communicating is informing or, in Montalt i Resurrecció & García Izquierdo's (2016: 82) words, "informing is an act of communication".

Ensuring the understanding in both aspects (oral and written) is also part of the act of communication. We cannot continue without referring to the tendency from which we work: user-centered translation (UTC) context-oriented and participant-oriented according to Soujanen *et al.* (2015) classification. It is advisable to explain that we talk about the translation of the informed consent form since it is the object of this study but this subject can be extrapolated to interpreting, since the procedure of communicating the informed consent is carried out orally when the context is multilingual and a form in the patient's mother tongue does not exist, so the interpreter intervenes.

Since 1980, the tendency in translation and interpreting has been oriented to the functional theory centered on the translation purpose. Nevertheless, Nord (2012: 32) mentioned the existing gap of applying theory to practice due to the difficulty entailed:

Audience orientation has been a particularly sensitive aspect of functionalist theory and applications from the start. Critics have been asking how translators know what the audience expects of a translation. Indeed, it is easy to talk about the audience's expectations but much more difficult to obtain empirical proof of what audiences (for certain genres or in certain non-linguistic fields) really expect.

Two of the main aspects in this current as applied to medical interpretation that enable us to bring to light the need of knowing the user's expectations on this tendency to the active patient are usability and user experience. Following the authors' description (Soujanen *et al.* 2015: 2):

[...] Usability refers to the ease with which users can use a product to achieve their goals [...] according to their expectations and without obstacles or hindrances. [...] User experience is a holistic concept which includes all the user's emotions, beliefs, preferences, perceptions, physical and psychological responses, behaviours and accomplishments" (Soujanen *et al.* 2015: 13).

Related to usability, an emerging concept is intuition, also defined in Soujanen *et al.* (2015: 16) as "*our familiarity with something in light of our earlier world of experience with it*".

It is pertinent to mention these authors' statement due to its pertinence to the object of study context: "*translators are the user's representatives, and as members of design teams, translators can help to create a full user experience*" (Soujanen *et al.* 2015: 13).

### 2.3 Medical texts addressed to patients: the informed consent

Medical writing and translation field includes different text types. Nevertheless, as we have previously announced, we focus on the informed consent defined in the medical texts type addressed to patients and family according to Gil Alberdi's (2009: 39) classification.

It is one of the most important documents in healthcare research and, thus, medical translation. We adhere to the opinion of several authors who agree on the fact that informed consent clearly shows that texts for patients are not always as understandable as we would like them to be (Valentini *et al.* 2013; Prieto Velasco 2014). Words by Valentini *et al.* (2013: 1) stand out, also included in Prieto Velasco (2014: 32):

A large literature supports the notion that the language used is not comprehensible to most people. Subjects may not fully read [informed consent form] because it is too long, they do not understand it, and are confused by medical and legal terms.

One of the reasons, as indicated by Montalt i Resurrecció & González Davies (2007: 60), is that the previous knowledge of the prototypical users of this text type is not taken into account when writing the texts. Along these lines, in Villamañán *et al.*'s (2016: 210) words: "to obtain the signed informed consent implies that information has been provided previously, adapted to their level of understanding". Nevertheless, how is the information adapted to this level of understanding?

In this way, we can state that some differences are noticed in the conceptual and linguistic plan, which brings us to research questions like: Which role does the interpreter play in this context? How is oral modality combined with the written one? Which impact can language barriers create regarding comprehensibility?

After our inquiries, among the possible authors of informed consent forms, there are doctors or nurses, hospital administration staff, pharmaceutical companies, medical supplies companies, health organizations, government agencies and insurance companies. Due to the authors' diversity, elements such as the content, style, vocabulary and nuances vary in each document. They are created for a generalist public without applying patterns like age, gender, intellectual level, etc. This fact implies comprehension difficulties given that the audience usually has very diverging features and very particular needs.

As Gallego Borghini (2015: 17) expresses, in 1999 Ordovás *et al.* already came to the conclusion that for a good understanding of 97% of informed consents it is essential to have mid-level or higher education, given that we are referred to the previous idea of comprehensibility and complexity of understanding the informed consent.

This work holds on a line of research relative to the perception that patients have on the communication quality. In this context, recent studies of Longacre *et al.* (2015) and Mazzi *et al.* (2016) stand out, also mentioned in Montalt i Resurrecció & García Izquierdo (2016: 82).

### 3. Comprehensibility as an essential factor

Some documents such as the informed consent are used to transfer specialized information. Doctors' explanation of the information contained is seen as the way to make it accessible to patients who share the language of the speaker but who are not at the same level of knowledge on the subject.

In this act of transmission and accessibility, one of the aspects that has caused great concern from the medical, ethical and linguistic point of view is the comprehensibility problem. In our approach we are focused on readability and the medical users' perception. Text readability, as Prieto Velasco (2014: 31) writes and it is related to our study context, "should be understood as the set of linguistic features to facilitate text reading". It is necessary to mention that visual readability (legibility) is also included in the study in terms of conceptual difficulty levels users have to face to understand the text (Wolfer 2015; Prieto Velasco 2014).

Several authors have made proposals to improve comprehensibility such as the following: Meyer & Mackintosh (2000) delve into the technique of determinologization understood as the mechanism to make semantic changes in the terms that are used in the common language; Mayor Serrano (2008) writes about simplifying the structure and making changes at the microtextual and macrottextual levels; Muñoz Miquel (2012) compiled the reformulation procedures to improve comprehension such as restructuring the text as a whole, selecting the most relevant information, incorporating visual elements, highlighting key words, delimiting sentences and simplifying complex syntactic structures, among others, and Campos Andrés (2013) analyzes different resources such as definition, synonymy or analogy to ensure communicative effectiveness. However, our proposal includes a novel factor due to the introduction of the interpreter as a specialist in communication management and expert in language and culture to reformulate and adapt written information orally and in an understandable format for the patient. These techniques can range from determinologization, through empathy, to the use of audiovisual resources.

#### 4. Empirical-analytical research on comprehensibility and communication

##### 4.1 *Materials, methods and informants*

The starting point of this project comes from the publication of the Decalogue of informed consent developed by the Central Ethics Committee of the Medical College Organization (COEM 2016). The document is especially relevant for the figures shown, among them, we underline that 70% of healthcare complaints are related to the information and informed consent failures.

The study carried out has as its material base a compilation of *ad hoc* corpora from the results of different search strategies of repetitions and concordances with *AntConc* tool. Finally, corpora are composed of six informed consents pertaining to the dentistry speciality in Spanish and its translations

into English, thus, 12 texts altogether. We must explain that it was decided that they were from the same speciality so that the sample was homogeneous and the results were exact. Informants are divided in three groups according to the methodology and goals of the study. On the one hand, there is a first group of dentists who have been working in private healthcare in Spain between 12 and 15 years and stay in touch with a considerable volume of foreign patients. On the other hand, two groups of patients were created: one group of five Spanish patients and another group of five British patients. All of them pertaining to the same age bracket (45-60 years) and formed each one by 3 women and 2 men due to availability reasons. The methodology employed in our research is double: qualitative, through several groups of discussion (focus group), and quantitative through a survey for patients and another one for health professionals. The results of both methods are complementary with each other.

Three groups of discussion have been created: dentists, Spanish patients and British patients, according to the division of the informants' groups. In the first part, focused on health professionals, after the focus group, they have individually answered several semi-structured questions extracted from Valero Garcés (OFRIM 2011: 118-132) study in order to test their viewpoint of the assistance quality for foreign patients and the interpreter's role. So, in the second part, focused on patients, two focus groups have been made (one with British patients and another one with Spanish) following the same scheme. Those groups have followed a reading phase of two informed consents which are part of the corpora (one about tooth whitening and another one about implantology) and a survey to confirm the perception described in the focus group about the comprehensibility degree from reformulating questions or restatement, in other words. In order to develop the survey for patients, a five-point LIKERT scale has been used where 1 is equal to totally agree and 5 is equal to totally disagree. The materials for British patients have been the translations into English of two consents used and the same survey in English. The reason why we have worked with each group of informants in their mother tongue is linked to our goal of discovering a comprehension degree firstly in their mother tongue in order to analyze later how the interpreter helps with its comprehensibility when there are not texts in the users' mother tongue as it is different from the official language of the country where they are.

#### *4.2. Research and results*

In the study addressed to professional dentists, in the focus group different topics were covered concerning interpreting and the informed consent.

Regarding the questions on their knowledge and expectations of an interpreted consultation, they indicate that they have some notions about an interpreter's job thanks to the daily contact established but they have not been prepared to work together. The informed consent forms with which they daily work are generalist, that is, professional college samples adapted only in formal aspects such as the logo, the medical license number or some risk associated requiring to be mentioned that is not in the sample.

Normally, in the specialized information transfer appearing in the informed consent, they give priority to the written part since it is the one reflected and the oral part is focused on a clarifying comment to answer doubts that the patient may have. That is to say, in multilingual contexts, the health professional gives the informed consent form (written mode) and the interpreter does the sight translation (oral mode). At this point, the current reality in the consultation appeared, even though it cannot be generalized given that the sample is not big enough; it is true that they described unusual occasions in which the interpreter has been alone with the patient which leads to the fact that if there are doubts, they have to look for the professional so that he comes back to the consulting room and explains all the doubts. As disadvantages to this practice, we notice the consequent deceleration of the process of the consent comprehension by the user since the process is interrupted while the professional comes back to the consulting room. We reiterate that it is on unusual occasions since every time they have an interpreter, they feel more relief because of their reliance in being an expert in language and culture. Finally, according to their perception, the comprehension problems of patients come from the difficulty they face since they do not have wide knowledge about this matter most of the times. On the other hand, in the survey that health professionals answered, the questions were related to the perception about the interpreters' role. For instance, a 100% agrees on the fact that the medical interpreter must explain backgrounds and meanings of the foreign consultation apart from clarifying technical terms to the users. In other tasks there was more disparity of results; for instance, regarding whether the interpreters must clarify imprecise statements by asking directly to users where 80% considers that they must do so. Moreover, for three of the survey respondents, the interpreters must omit secondary statements in order to avoid the waste of time as opposed to two who answered that they must not avoid them. Based on the results, it is reflected that there is still a gap of knowledge and some vague limits on the interpreter's role in some fields like healthcare.

Patients are another group of informants. In the research of text legibility through a semi-structured survey, we can mention the following example extracted from the sample studied with Spanish patients:

- 1) Participant patients were asked about the comprehension of several paragraphs as a whole like: “communications with sinus or nostrils rarely happen. There is even the chance to wound the maxillary sinus and provoke a sinusitis” (*“raramente pueden producirse comunicaciones con los senos nasales o con las fosas nasales. Existe incluso la posibilidad de lesionar el seno maxilar y provocar una sinusitis”*). Participants answered that they disagree with the exception of one of them who marked the option “totally disagree”. In order to confirm the degree of difficulty, apart from questions like the previous sample, another type of questions was composed where there were some blank lines so that they could explain with their own words the meaning of the previous section. Following the previous example, three of the participants did not give any idea with their own words and did not try to reformulate because their comprehension of the paragraph was very low and two of them tried to give some ideas like “it is related to the nose” or “something that does not usually happen but can happen”. Therefore, with this type of answers, it is observed that the problem of comprehension lack is caused by specialized terms like “communications” or “sinusitis”.
- 2) On the other hand, when the study is made with British patients, it is also confirmed that the general idea of the paragraph has been understood in broad terms. Nevertheless, the complete meaning is not understood given that they are not an expert audience. Therefore, the more facilities they are offered, the greater the degree of comprehension and restatement will be for taking founded opinions. However, we should explain which part has to offer facilities since currently/for the time being it is not stated that it is the interpreter who has that function even though at present it happens repeatedly. Thus, it is confirmed that the medical interpreter’s role in the dentist consultation is not defined. Such was the case that the integration of interpreting in the moment of the informed consent has not been studied in depth so their limits are vague.

In order to come to these statements, we show some relevant data such as the result about the comprehension of the term “filling” in the survey for British patients. All informants answered “agree” to the comprehension of the term given that there is not a synonym in a more formal register. Therefore, as it is

used in general language, the comprehension is total. Nevertheless, in the question about the term “peroxides” in the sentence “to prevent possible unwanted effects it is essential that you warn us of any allergy (particular to peroxides)”, it is not understood by the informants although, as they had context, 2 informants chose “undecided”, 2 “disagree” and 1 “strongly disagree”. That is why the scales have not tipped in favor of total incomprehension but, even though the term itself is not understood, the context is helpful. To this research about text legibility, we can add another example about the comprehension of “canine teeth whiten less than incisors”. This time, as there is context and it is not only an isolated term, the general idea is understood by all the informants obtaining a result of 4 informants undecided and 1 agree.

Regarding the research and discovery of patients’ expectations during the focus group, they indicate that the figure that can best make cultural nuances in the consultation is the interpreter because of the anticipated preparation. Moreover, they mention in the focus group that if the health professional who looks after them is from another nationality or has stayed abroad he/she may also know how to clarify some cultural conflicts. Nevertheless, in their experiences, whenever a cultural conflict has arisen in their consultations, the interpreter has satisfactorily solved it and when one of them was occasionally in a minor cultural conflict and without an interpreter, they have had difficulties to solve it even though it was not a very important conflict.

As we have previously mentioned, visual legibility is also included in this study. On this matter, the patients who were asked about whether the inclusion of pictures in the informed consent forms helps them to totally understand. In their opinion, in order to make comprehension easier, it is a useful resource as a clarifying tool especially in the procedure part. Apart from the pictures, audiovisual resources or models provided during the consultation have been very useful when they could have them even though this happened on rare occasions. It is necessary to explain that they are very helpful for the British patients group that has the added difficulty of occasional access to documents in their mother tongue.

Other topics dealt with in these focus groups were the reading habit of consents, the signature moment and the doubts resolution. In the case of foreign patients, comprehension problems are also present in their own mother tongue but mostly in their medical visits where informed consents are only in Spanish. When this last situation happens, the attempt at comprehension is totally reduced and so is the interest in reading those documents perfectly knowing their legal consequence.

## 5. Conclusions

The change of the healthcare model and the trend towards patient education bring about changes for which studies concerning the new practices are needed in the field of health interpreting. This work is seen as a contribution to this research line. It is important to clarify that although the English translation of informed consents has been incorporated into the corpus, nowadays, in the consultations in the Spanish territory, consent in the said language is not always offered. In other words, informed consent is usually delivered in Spanish and the interpreter is used to ensure understanding given that health professionals are not always willing to give a consent that they have not supervised due to their linguistic knowledge.

Although the informed consent has made progress in terms of patient empowerment it also has negative aspects like the lack of comprehensibility by some patients in the dialogue between the parties. That is to say, there is a gap among information statement and its adequate processing by the user. To make communication successful, the dissemination of specialized knowledge must be effective, and so must the care the patient should receive as an individual and not as a group or audience understood as a homogeneous group. The key in this context is individuality, the patient as an individual with different features and needs from any other patient. That is, the increasingly unstoppable need to personalize communication. In this sense, the need for studies and practices towards communicative effectiveness addressing multimodality management previously mentioned when written information is delivered orally by the interpreter becomes evident.

According to our results, multimodality is a benefit to foreign resident patients in Spain compared to Spanish patients because they are not provided with an intermediary as the interpreter does with foreign patients. This is why the interpreter replaces the lack of foreign patients' comprehension and gets involved in a mediation process which should be initiated by the doctor in monolingual and bilingual contexts.

To classify interpreters' role in view of informed consent in healthcare, we state that it is more in line with Patient Navigators approach (Crezee 2013) since the interpreter behaves as a communicator and solves cultural conflicts without taking a stance on the patient; advocacy roles are left behind. The key is communication; the interpreter is no longer a conduit as some approaches pointed out. The interpreter has become a communicator and is the professional profile in the medical consultation that best knows language, culture and patients' communicative needs. Furthermore, the interpreter knows the crucial points to adapt him/herself to the patient and empower his/her

comprehensibility level. Nevertheless, healthcare professionals' lack of awareness of interpreters' role results in difficulties in terms of teamwork. Yet, it is very important to differentiate interpreter tasks and extra tasks such as obtaining the informed consent.

However, activities such as the focus group encourage dissemination and raise awareness of interpreters' tasks. In everyday practice, communication factors such as empathy, emotions or clarity are taken for granted; therefore, lectures, talks or focus groups make healthcare professionals aware of these factors that can be thought of less importance or invisible when, in fact, they cannot be dodged.

Our main goal is to provide data to achieve a more appropriate communication based on mediation (interpreting, translation, proofreading...) to shed some light on patient empowerment and well-being as well as on all concerned parties.

Following our research and results, we noticed in the practice of medicine that most consents are signed blindly in this context and, generally speaking, the patient feels forced to sign it even though he/she does not understand the whole document of his/her procedure or treatment. Our approach is to refer to that practice as "veiled consents" –consents being understood as a patient decision instrument. So, the patient signs as if he/she was wearing a veil not to be allowed to see the content clearly. It has been classified as "blind consent" (Plaut & Bartlett 2012: 293-311). In terms of intralinguistic and interlinguistic perspectives and ethics, this situation is not acceptable due to the fact that it neither promotes comprehensibility nor treatment adherence.

Patient opinion research helps to establish the satisfaction level and results in specific data to be used to enhance communication among healthcare professionals, patients and interpreters. Therefore, all concerned parties need to pull in the same direction towards patient education and teamwork improvement. A short-term aim is to make information become communication. That is the reason why some research studies highlight the line this paper focuses on and they pursue clinical documentation, patient care and access to specialized information enhancement: that is the case of Saiz Hontangas *et al.* (2016) on patient information leaflets or Toledo Chávarri *et al.* (2016) on chronic patients' uses and needs and written communication. In short, the clear need to move from text to context and to personalize communication to ensure its effectiveness is vertiginously growing.

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