

JUNTS methodology for creating web apps to bridge the gap in doctor-patient communication: the case of COMjuntos application in the field of rare diseases

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Research

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Abstract

Background: The diagnosis or even the suspicion of disease has an emotional impact on the patient and their families and generates a need to acquire relevant knowledge and skills in a short period of time. These patients will sometimes face cognitive barriers in their communication with the professionals. These barriers can have a negative effect on knowledge acquisition and, affect their relationship with clinicians. Results : The JUNTS methodology, helps patients manage the communicative situations they and their family members find themselves by exploiting a polyphonic design that includes different levels of involvement. One of the characteristics that makes this approach unique is that patients and representatives of patient-support associations work jointly with health professionals, in designing the contents of a patient-support application. The methodology exploits a modular structure centred around a series of short challenges with different types of user involvement (visual, textual and hypertextual). For optimal adherence elements of persuasive design have been integrated. Conclusions: In this paper, we outline how the JUNTS methodology has been used to develop the COMjuntos app. This web app has been specifically designed to help families who have a child with a rare disease empower themselves in the main communicative situations with health professionals.

1. Background

The diagnosis, or even the suspicion, of a chronic disease makes patients aware of their need to acquire both the knowledge and competences that will ensure they develop the highest possible degree of self-care and autonomy in the management of their disease (1). Yet, it can be far from straightforward for a diabetic, for example, to understand why they need to inject themselves with insulin and to learn how and when to do so, or for those affected by rare diseases to follow the steps for administering a specific treatment. Equally, many patients can find it extremely challenging to put questions to a specialist about a given medical test, diagnosis or treatment that is unclear to them. In such situations, patients face a series of physical, linguistic and psychological barriers that in many cases will determine how successfully they are able to adhere to their therapeutic regimen and comply with their medical prescriptions (2).

There can be little doubt that underpinning the whole process of a disease, and in particular the non-expert patient's acquisition and learning of these new concepts, doctor-patient communication is of great importance and is closely related, for example, with adherence to treatment. The factors that affect this communication are multidimensional and include aspects related both to health systems and, at a more individual level, to escalating patient demand, staffing problems, and a lack of empathy and personalised care. In contrast, among the factors that can enhance communication is the medical attention that takes into account patients' beliefs, needs and preferences, and which, therefore, is more carefully tailored to the individual (3).

Doctor-patient communication is especially complex because it is always unequal and often unidirectional: the clinician is the one with the knowledge about the disease and the power to help, treat

and cure the patient; moreover, the doctor controls the space in which the communicative acts are played out, since it forms part of her workplace. In contrast, the patient, as the non-expert finds himself in a very vulnerable situation, involved in a communicative act about a health problem and, with little understanding of his illness, he may well feel afraid, confused and even embarrassed, while perceiving the hospital space to be hostile. These communicative acts may be oral and, therefore, ephemeral – medical visits, tests, consultations, etc. – but may also be written – medical reports, a patient’s informed consent, treatment plans, etc. – and, in this case, they are permanent and can be consulted by the patient in their own home (4).

In the case of rare diseases, that is, those that affect less than one in 10,000 people, and which are calculated to number around seven thousand (5), patients face a situation in which effective doctor-patient communication acquires a central role. In the case of rare diseases such communicative acts are especially frequent (given the chronic nature of these disorders) and so they come to form the basis of an appropriate level of empowerment of patients and their families (6).

The communicative acts involving patients and health professionals are threatened by the difficulty that patients and their relatives have in understanding the messages that the professionals wish to transmit. In the case of rare diseases, this problem is often exacerbated as clinician involvement tends to be even more intense (7). These demands, however, can clash with difficulties related to both the complexity of the diseases and the pressures of care, the lack of knowledge and the time professionals have available to dedicate to their patients (6).

In addition to the importance of communicative acts in treating chronic illnesses, in general, and rare diseases, in particular, the level of the family’s health literacy is critical for their empowerment and for ensuring they acquire a perception of control in managing the medical condition and its psychological and social impacts (8). Here, we understand health literacy as the capacity, motivation and competence to “access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” (9).

Unquestionably, adequate health literacy is fundamental in the correct management of complex disorders such as rare diseases and is one of the challenges that has to be successfully faced in order to improve the quality of life of patients and their families (10). In this regard, an equally important challenge is that of identifying and minimizing the cognitive interferences that can be transmitted via the language and, especially, the terminology used by professionals.

Low levels of health literacy can also lead to difficulties in accessing the requisite healthcare, understanding the information provided by health professionals, and adhering to treatments, and can, in turn, result in an increased number of hospital admissions and visits to A&E departments and family doctors. For example, the use of communicative and linguistic strategies that facilitate comprehension helps patients gain a better understanding of the information that clinicians seek to convey to them in written texts. These strategies can usefully include: a) using simple and appropriate syntax, b) employing

explicit pragmatic connectors to facilitate the interpretation of information, c) explaining semantically opaque terminology, d) defining all acronyms and abbreviations, e) ensuring that the punctuation used facilitates interpretation and f) using metaphors to clarify complex ideas, etc. In addition, when presenting the information, the use of colour codes, images, videos, etc. is recommended to boost comprehension and, in this way, people can become more health literate and the barriers between doctors and patients can be removed (11).

To overcome the problems described above, we present an application that serves to guide patients in their communication with health professionals. In the first place, the app is developed from the case study of a rare paediatric disease, but we believe it can be readily extended for use with any other type of chronic disorder.

This paper has two main objectives. First, it presents the JUNTS methodology and, second, it describes COMjuntos, an application of the JUNTS methodology to a specific case: that of rare paediatric diseases. The COMjuntos application aims to help families with a child with a rare disease to cope with the main communicative situations they find themselves in when engaging with health professionals. The aim is not to provide knowledge about a specific illness, in this case rare diseases, but to anticipate the obstacles that may arise in the communication with clinicians and to provide the families with the strategies that enable them to feel empowered and to manage the day-to-day problems they face in dealing with their child's illness.

2. Results

Basic principles of the JUNTS methodology

The development of the JUNTS methodology follows a series of design principles that are identified and summarized below in Table 1.

In what follows, the five design principles underpinning the JUNTS methodology are outlined and exemplified by their application to a specific case: COMjuntos, a web app that includes specific communicative situations in which families feel they may not have sufficient resources to cope. The communicative situations addressed by COMjuntos are those that families encounter once their child has been diagnosed with a rare disease. They include, for example, the need to understand a medical report, having to undergo clinical tests, the search for additional resources, a doctor's visit, and the search for support associations.

In COMjuntos application linguists and psychologists worked alongside educational psychologists – experts in learning design – to develop an application that promotes family health literacy. The app provides content endorsed by health professionals (specifically, doctors and psychologists) and

combines the use of controlled language with linguistic strategies adapted to the non-expert to facilitate understanding. The COMjuntos application is available in different formats:

1. In a downloadable app format for both IOS and Android devices
2. In web format: <http://appCOMJUNTOS.es/>
3. In book format, both printed and as a downloadable pdf: <http://appcomjunts.es/wp-content/uploads/2018/11/ES-libro-COMJUNTOS.pdf>

All versions of the COMjuntos application are available in open source ensuring they are accessible to the entire target population.

Principle 1: Design centred on patients' needs

The active participation of patients is essential in the design of any intervention that specifically targets that group and is especially relevant in the case of those affected by a rare disease (5). In our model, we employ four strategies to harness patient participation as a method for identifying their needs and as an additional means for ensuring their involvement in the project: first, patients are interviewed in-depth; second, two focus groups are set up – in this instance, conducted on FEDER premises; third, a linguistic analysis is made of a corpus of real medical reports with the aim of identifying the factors that impede understanding (12); and, fourth, a survey is carried out comparing patient comprehension of a real report and the same report once it has been enriched linguistically and cognitively (13).

This methodology – adopting a user-centred design framework – is inspired by proposals made initially by Witteman (14). The framework, developed in response to evidence that a concept such as *patient participation* is overly ambiguous and subjective, is based on three elements: understanding the user, developing a prototype and observing how users interact with that prototype.

Application of the patient-centred design principle to COMjuntos

In the case of the COMjuntos app, to “understand the user”, we conducted ten in-depth interviews (15). Later, various working meetings were held with experts and representatives of FEDER associations, in which, in addition to contributing to content creation based on their personal experience, participants were asked for feedback on the contents being developed.

Likewise, to “observe how users interact with the prototype”, different versions of the first prototypes were tested, both by the experts (who had, in fact, participated in their design) and by patients and representatives of rare disease associations.

Principle 2: Persuasive design

Persuasive design in the field of technological applications has been defined by Fogg (16) as the scientific discipline that studies the characteristics and attributes of technologies, particularly those of the so-called new technologies, to support a change in user behaviour, that is, persuading them without resorting to either deception or coercion.

Subsequently, various authors, including Oinas (17), based on Fogg's assumptions, have developed a complete system for the design and evaluation of online interventions aimed at promoting behavioural change: so-called Persuasive Systems Design or PSD (17). PSD classifies its design principles as support for carrying out the primary task (e.g. ensuring that the technology is simple and intuitive), support for dialogue (e.g. ensuring that the language is comprehensible and that the system strengthens the user's social role), social support (e.g. ensuring that the user can observe how other people behave in the same situation) and credibility (e.g. ensuring that the system leverages roles of authority to enhance its validity). By applying this model to our app, we can systematically observe how the persuasive system design categories are used and investigate their possible influence on treatment adherence.

Application of persuasive design to COMjuntos

In designing COMjuntos, a first prospective analysis was carried out in which, based on the principles of the Persuasive Systems Design model developed by Oinas (17), elements of this model were incorporated to increase the degree of persuasiveness of our application, with the aim of encouraging parents to use it (18). Some of the more relevant elements included a modular design based on challenges to facilitate the consultation of information, the use of colour codes (see Figure 1) to simplify even further the information and the use of fonts of different sizes and formats to help distinguish between basic and more specific information.

Another persuasive element employed was that of the principle of authority (the PSD Authority Principle), achieved via the participation in the videos of the Vall d'Hebron Hospital doctors and researchers, internationally recognized teams specialising in minority diseases, psychologists and members of the FEDER board, together with the parents of the affected children. They recommend appropriate ways of proceeding and suggest certain strategies in their role as experienced witnesses (the PSD Suggestion Principle).

Finally, the language of the content was analysed to ensure COMjuntos and, above all, the modular structure of the application, were appropriately simplified and readily understandable (PSD Reduction Principle).

We deemed it important that COMjuntos be made up of various modules that would help structure knowledge and the situations in which the patient might find themselves in real life. These modules, although they follow a certain chronological logic, do not need to be consulted in a linear fashion. Thus, the narrative thread of the COMjuntos app comprises five communicative situations that invite families to overcome certain situations they might find themselves in when having to communicate with a health professional. Adhering to the Reduction Principle, each module and all its contents are given a colour, as

shown in Figure 1. Thus, green is assigned to *Tenemos una enfermedad rara en la familia* [We have a rare disease in the family]; yellow to *Cómo preparar una visita médica* [How to prepare a medical visit]; brown to *Recibimos un informe médico* [We have received a medical report]; red to *Tenemos una prueba médica* [We have a medical test] and, finally, purple to *¿Qué más puedo aprender?* [What else can I learn?].

In turn, the different communicative situations are structured around a series of *Challenges* as shown in Table 2.

Principle 3: polyphonic and multichannel information design

Health issues are complex problems that can be addressed from very different points of view. Often, however, tools, applications and texts tend to be designed from a single point of view: either that of the doctor (medical report) or that of the patient. Here, by contrast, we argue that diverse voices (polyphony) on the same subject contribute to a richer and more complete perspective of the situation than that offered by any one individual voice.

Application of the polyphonic design to COMjuntos

Each of the seven challenges comprises: a) a video with real testimonies from affected families and health professionals specializing in rare diseases (paediatricians, doctors, geneticists, etc.), b) a hypertext that explains the situation and anticipates the doubts that usually arise, c) a basic dictionary of medical terms designed for non-experts and d) information including tips and links to resources, videos, associations, stories, etc.

Each of the texts is presented via the typical questions that are raised in the corresponding situation, since in this way we can anticipate the concerns, or potential concerns, of the patient or family member. In Figure 2, one of the app's screenshots shows a communicative situation with its two corresponding challenges:

In producing the videos – that is, the first level of access to each challenge – we opted for the polyphony of equal voices, so that each situation calls on the experienced voices of doctors, patients and relatives, association representatives, linguists and psychologists. In this way, each situation is always kaleidoscopic, which means we enrich understanding by drawing on the perspectives afforded by others: all are accredited voices, albeit with distinct value. All these groups have experiences to relate in order to ensure that communication between families and clinicians is satisfactory.

Principle 4: specific treatment of linguistic and cognitive interferences

Not all the app's users have the same communicative or information needs. Moreover, not all patients have the same sociocultural level or level of health literacy. For this reason, we propose a design that allows analysis and hermeneutics of the content at a range of levels.

Treatment of linguistic interferences in COMjuntos

Thus, the COMjuntos application can be consulted at different levels and so that each challenge can be addressed at the level of depth desired by the user:

- Level one: visual, by means of videos that introduce each of the communicative challenges.
- Level two: textual, by means of titles, general sections and specific sections that the user can drop down.
- Level three: hypertextual, by means of a dictionary of user terms and information in the form of hyperlinks to carefully evaluated and selected information available on the Internet.

In seeking to reduce linguistic and terminological interferences, we have taken into account the fact that users are not specialists in the health sciences. As such, they are likely to have difficulties in accessing the information transmitted by the professionals, since their cognitive structures in relation to health issues do not coincide. Several studies show that the use of terminology and the abuse of acronyms represent a major communicative barrier in this respect (19) (20). Consequently, one of the issues that requires most management in developing the application is the controlled use of terminology, that is, the lexical units of specialized communication which tend to concentrate the most specialized information.

If our goal is to ensure that the language is not an obstacle for the patient (21), it is important to pay careful attention to the words used to speak about health issues and to be sure that they will be understood or, if it is likely they will not be understood, that the means are provided so that communication is not affected. For example, not using a particularly high terminological density in written texts (less than 12%), explaining unusual lexical units, not using abbreviations without first providing their full form, avoiding the use of loan words, etc. are elements that help construct more understandable texts.

In the application designed here, special attention has been paid to the language used. In particular, we have sought to control what terminology is used and how it is introduced and explained in the text. Thus, explanatory paraphrases are embedded in the texts, all abbreviations used are given their full expanded form, and specialist terms are hyperlinked to an *ad hoc* glossary with definitions appropriately worded for the non-specialist patient. The vocabulary can be accessed directly or through the text's terminological units which have a hyperlink to the glossary (see Figure 3). The texts and the vocabulary have been prepared by the team's researchers and reviewed by linguists, psychologists, doctors and geneticists.

Science that studies alterations of the DNA, both in genes and in chromosomes, using advanced techniques that allow an accurate diagnosis of some genetic diseases]

Principle 5: dissemination via specific channels

The application is based on the idea that its format should never constitute an obstacle for accessing health information. Sørensen (9) in relation to health literacy considers that:

Health literacy is linked to literacy and entails people's knowledge, motivation and **competences to access**,^[1] understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.

In rare diseases, access to information, as a basic and essential element for improving health literacy (as defined by Sørensen), acquires critical importance. Therefore, we opted to implement the application in multiformats to guarantee the primary necessity of health literacy: namely, that people can actually access the information they need.

Dissemination via different channels and formats of COMjuntos

Since 2018, FEDER (Spanish Federation of Rare Diseases) has recommended the application to its members via its home page. In this way, as well as certifying the quality of the application, COMjuntos is available to all users of its website. In addition, in 2018 COMjuntos was recognised as the best patient app at the e-Health Awards and this has helped further its dissemination (see Figure 4).

It is also important to ensure that users do not face any technological barriers in accessing information. Therefore, the application has been designed for use in different formats: app, web, print book and downloadable e-book. In addition, all videos are subtitled so that people with hearing difficulties can access the information. Another barrier is often the economic one: but, here, access to the tool is totally free. At the technical level, it was considered that in order to promote knowledge and the use of the application, it should be available, free of charge, in different formats adapted to any type of mobile device. A web version is also available that can be accessed from any internet browser. In addition, there is a print version available for those who prefer to read the materials without using new technologies. Finally, this book can also be downloaded in *pdf* format – the Spanish version being illustrated in Figure 4:

The app is light, occupying only 36 MB of storage space and consuming very few resources of the processor being used. Navigation is highly intuitive. COMjuntos is currently available in both Spanish and Catalan.

[1] The bold is ours.

3. Discussion

The JUNTS methodology embodied in the COMjuntos application has a number of obvious strengths which we have striven to highlight throughout the above presentation and which we summarize below:

1. It is based on real patient needs
2. It employs a persuasive design
3. Knowledge is broken down into four levels of involvement (hermeneutics)
4. Knowledge is transmitted in a polyphonic fashion
5. Professionals are given a voice alongside that of the expert patients
6. The language is highly controlled, especially the use of terminology
7. The information is supported by glossary of the terminology used with explanations tailored for the patient
8. It can be consulted in different formats, both digital and print
9. It is adapted to people with hearing difficulties
10. It is disseminated via patient groups and associations

4. Conclusions

COMjuntos is the first application to use the JUNTS methodology, developed from research into clinician-patient communication from both a linguistic and psychological perspective. We are convinced that the same structure and methodology can be applied to other diseases or chronic health conditions with similar benefits. COMjuntos has the capacity to transform, because, being based on real communicative problems, it provides solutions for the affected population and, moreover, it has a high inclusive potential since it actively and responsibly involves society. As such, it is a good example of knowledge transfer whereby research results are channelled back into society in the form of an application.

Declarations

- Ethics approval and consent to participate

We have been requesting the consent of all the patients/doctors/families that take part in the development of our study. We do not collect health or personal data from people.

- Consent for publication

We included the scientific exploitation, including publication in our consent form

- Availability of data and material

We can share anyone our material.

- Competing interests

We haven't competing interest

- Funding

This study has been conducted within the framework of the broader Project: TOGETHER: overcoming socio/educational barriers and promoting literacy on the interferences and difficulties in understanding information and documentation aimed at families of children affected by rare diseases.

RecerCaixa 2015. Avancem amb la ciència. ACUP and Obra Social "La Caixa". PI: Rosa Estopà (Universitat Pompeu Fabra) and Manuel Armayones (Universitat Oberta de Catalunya). URL: https://www.upf.edu/web/medicina_comunicacio

- Authors' contributions

Dra. Rosa Estopà and Dr. Manuel Armayones have been participating in the whole part of paper writing, editing in a collaboratively way. We had been PI of the project that has been allowed design our model

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Tables

Table 1.- Characteristics of the JUNTS methodology

Design based on patients' needs	Using in-depth interviews
	Integrating patients in research team
Persuasive design	Applied to the design of the application
	Applied to its content
Polyphonic and multichannel information design	Polyphony (many-voiced)
	Multichannel
Specific treatment of linguistic and cognitive interferences	By means of linguistic analysis
	By means of didactic treatment
	By compiling glossaries/dictionaries
Dissemination via specific channels	Patient organisations
	Scientific events for patients
	Multiformats

Table 2: COMjuntos communicative situations and challenges

Communicative situation	Challenge
<p>we have a rare disease in the family The day the doctor communicates to the parents the diagnosis or possible diagnosis of their child</p>	<p>Challenge 1 What is a rare disease?</p>
<p>How should we prepare ourselves for the medical visit? When the family has a doctor's visit</p>	<p>Challenge 2 What do we want to achieve during the medical visit? Challenge 3 What can we do during and after the medical visit?</p>
<p>we have received a medical report When a clinician gives you a written medical report</p>	<p>Challenge 4 What can we do to understand a medical report correctly?</p>
<p>we have a medical test When your child has to have a medical test</p>	<p>Challenge 5 What to ask the doctor when he sends your child for a test? Challenge 6 How to prepare your child for tests?</p>
<p>What else can I learn? When we do not know what else can be done</p>	<p>Challenge 7 How can I learn from other families?</p>

Figures



Figure 1

COMjuntos modular structure organised by colours



Tenemos una prueba médica



¿Que preguntar a mi médico cuando prescribe una prueba a mi hijo?

Listado de preguntas que podemos plantearle a nuestro médico cuando nos diga que tenemos que hacerle una prueba a nuestro hijo.



¿Como preparar a mi hijo para las pruebas?

Cómo hacer que nuestro hijo pase por la prueba médica con el menor estrés posible.



Figure 2

Screenshot of Challenges 5 and 6



Diccionario básico de términos médicos

Figure 3

Screenshot of the application's glossary [Science that studies alterations of the DNA, both in genes and in chromosomes, using advanced techniques that allow an accurate diagnosis of some genetic diseases]

Presentación

Premio eSalud 2018 – eHealth Awards 2018 a la mejor app para pacientes

COMjuntos es una aplicación que ayuda a las familias que tienen un niño o una niña con una enfermedad rara a gestionar las situaciones comunicativas con los profesionales de la salud. El hilo conductor de la aplicación son 7 retos que invitan a las familias a superar algunas situaciones, como el día que les comunican el diagnóstico, cuando tienen una visita médica, les entregan un informe médico o deben realizar una prueba médica. La originalidad de COMjuntos, y de estos materiales, reside en **valorar la importancia del lenguaje cuando se está hablando de salud** y ayudar a empoderar a los padres y familiares para que logren comunicarse exitosamente con el profesional de la salud que acompaña a su hijo y mejorar el proceso de acompañamiento que implica este tipo de enfermedades tan poco frecuentes.



Premio eSalud 2018
eHealth Awards 2018
Mejor app para pacientes

Descarga nuestra app



Descarga nuestro libro



 <p>Tenemos una enfermedad rara en la familia</p>	 <p>¿Cómo preparar la visita médica?</p>	 <p>Recibimos un informe médico</p>
		

Figure 4

COMjuntos – winner of the eHealth Awards’ best app for patients, 2018