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The Role of Information Design in Reducing Dependence on Health Services

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ABSTRACT

The dependence and passivity on health services is due to various factors such as the inadequate literacy levels of the population, the hegemonic model that still prevails, and the lack of interaction between users and health providers. To reduce this dependence, health information needs to be delivered to people outside traditional places, like hospitals and health centers, and incorporated into everyday life. The paper discusses how information design can contribute to this change by analyzing cases and literature on the topic, with a focus on the clinical analysis report. It also emphasizes the importance of designing health messages that cater to the cognitive, cultural, emotional, social, and linguistic needs of citizens, rather than ignoring them. By doing so, it enables an innovative, integrative approach that favors citizen autonomy and reduces the passive attitude related to health services and providers.

Keywords: Information design, Health literacy, Human behavior, Health services, Cognitive needs

INTRODUCTION

Currently, the watchword in health is “health literacy”. Health literacy equips individuals with skills that make them able to read and understand information and better manage their health (Nielsen-Bohlman et al., 2004), not only when adhering to therapies and treatments, but also when promoting health and preventing disease.

It is interesting to notice and reflect that, nowadays the access to information that we are all submitted, does not mean more knowledge. If that question was true, we would not witness so many unnecessary trips to health services, nor the exponential increase of non-communicable diseases, consequence of risky behaviors and unhealthy lifestyle habits.

Changing lifestyle habits is a difficult process that already contains obstacles that hinder change; so, if the tools and information resources developed to promote behavioral change are an additional obstacle, we will hardly see the desired change. It is essential that people recognize the value of information and knowledge and feel the need to integrate them into their daily lives. To do so, this information has to be perceived as a useful tool in the pursuit of health – as a resource, not as a purpose. In other words, information has to be designed taking into account people's specific informational needs, such as the ease of identifying and understanding it so that they are able to transfer it into effective action, allowing them to recognize the impact that these changes can have on their lives (Fishbein & Cappella, 2006).

Through this research we will seek to relate the process of constructing health information messages with increased autonomy and decreased need for access to the National Health Service. In order to describe this, we will review a medical information document – the clinical analysis report – a document that the general population has access to and that can be used as a vehicle for information and knowledge.

THE RELEVANCE OF DESIGN IN THE CONSTRUCTION OF HEALTH KNOWLEDGE

According to the World Health Organization (WHO), health communication is a complex social process, but it has the ability to contribute to health outcomes. The potential of the development of health information communication strategies – to make users particularly active and receptive to behavioral change – is already recognized (Abraham & Kools, 2012).

Communication between doctor and patient in a consultation context is fundamental to all clinical practice and is achieved through verbal and nonverbal behaviors. Through communication it is possible to explore and value symptoms and feelings, to identify and model expectations, to give explanations and agree on therapeutic plans, to prevent accidents and errors.

On the other hand, the user, as a patient, must be empowered with the knowledge to be correctly involved in decision making, not only to correctly manage the disease, but also to be able to communicate effectively with doctors and other health professionals.

Studies prove that patients who are part of decision making about their health, are more likely to have better health (Hibbard, 2003 cited by McCarron et al., 2019). Furthermore, about financial terms supported by the state, if a singular citizen has a counselor for nine months helping them prevent diabetes is much more beneficial than fifteen years of dependence on insulin injections and regular visits to the doctor.

Thus, in the context of health care, it is crucial to convey information as transparently as possible. To this end, the recognition of cultural and educational variables is determinant (Rosário, 2009), so it is important to create spaces for reflection, debate aspects and establish appropriate forms of communication, not only with patients, but also with family and friends.

Poor communication in health leads to patient dissatisfaction, errors in diagnosis and assessment, difficulty in achieving results, and a worsening of the physical and mental health status with the provision of ambiguous information leading to patients feeling misunderstood and sometimes ridiculous (Dinarés, 2009). These situations exacerbate the patient's condition and contribute to the increased need to turn to health services.

Outside the clinical context, access to information is facilitated by the abundance of available means, both in terms of quantity and speed of access. However, inaccurate or excessive information can be harmful, promote error and poor decisions, causing greater uncertainty and confusion. So, accuracy is mandatory and information has to be filtered to be useful, relevant to the purpose, clear and with the necessary degree of detail, organized, presented in the appropriate medium, accessible and flexible (Jacobson, 1999).

Although the content of existing information is usually relevant, it often fails because it does not consider the informational needs of the audience, their characteristics and literacy (Nielsen-Bohlman et al., 2004), and in the way it is presented.

Health messages that aim to change behaviors should include strategies on how to incorporate concrete actions into everyday life, such as identifying obstacles and suggesting solutions of how people can easily adapt to these actions in their lives, and whenever possible present the impact that this change will have on people's lives (Stadler et al, 2010). To study this situation, Stadler (2010) exposes two groups of women to information about the benefits of eating five pieces of vegetables and fruit daily. While one of the groups had contact only with the recommendations, the other group had access to the same recommendations but also to self-regulation techniques, that consisted in the recognition of their greatest desire regarding the diet, identifying the best result and the most critical obstacle. From the interaction with the second group they could design their intentions: when and where the obstacle occurs and how to overcome it; when and where occurs the opportunity to prevent the obstacle; and finally identify where is the opportunity in order to achieve the goal. They observed that the first group was able to maintain this change during the first four months, while the second group continue to maintain their daily habit of eating five pieces of fruit and vegetables after two years.

The main challenges facing the developing of health messages are: on the one hand health messages have to compete with commercial messages that point in the exact opposite direction of health promotion messages (Jansen, 2017), but on the other hand they usually have a lexical complexity of information that makes difficult for the audience to access the message; thus resulting from the existence of several sources it makes difficult to perceive the credibility of the content; its presentation, organization and structure.

If to design health messages is a big challenge, creating messages that aim to change risk behaviors is an even greater challenge. To fulfill their purpose, those messages must promote the interest of the target audience, ensuring that it is understood, and to achieve this goal the content must take into account the diversity of the audience that comes from different backgrounds: ethnicity, beliefs, values, culture, identity, health literacy, among others. Thus, these messages must be constructed with awareness of the individual's specific beliefs and values and not just in theory, translating abstract knowledge (cognition, emotion, and social process) into effective health messages. In this way they promote acceptance and reflection on the topic, contributing to its memorization and a greater likelihood of acting on problems.

It is expected from the field of information design that this task will be solved. Defined as the art of preparing information that can be used by humans effectively, the main objective of design information is to develop documents that are understandable, quickly and recoverable, and easily translatable for effective action (Jacobson, 1999; IIID, 2007; Sless, 2009). This requires that information design considers the users of the information, understand and simplify complex relationships and, although these relationships are from disciplines other than design, it is essential that these messages are communicated in an appropriate way to the user.

THE IMPORTANCE OF HELTH LITERACY IN CLINICAL REPORTS

Excessive access to information and use of content, which is delivered to the individual through different media and in a fragmented way – most of the time without the depth, scope and detail needed for critical and creative thinking – promotes passivity and reduced cognitive capacity (Hoogeveen, 1997).

Moreover, a poorly literate individual, with low health literacy, in addition to having the most difficulty accessing knowledge, is usually the one who least recognizes the importance of literacy. Medical information documents often exceed the reading capacity of users, especially those with inadequate literacy levels.

Thus, although the population currently has access to a large amount of information about health in general and about their own health, they are not prepared to recognize and act upon it.

One of the information supports that we analyzed in our study was the clinical report. The choice of this instrument is due to the fact that people consider it as a proof of health, and a useful instrument to detect serious problems by seeing these results as a diagnostic tool (Van Bokhoven et al., 2006). Medical information through this resource is highly valued, corresponding to one of the main ingredients to which patients have access, which encourages and facilitates greater involvement in decision-making and self-management of health.

When the patient is prepared to receive information about the state of health, through the visualization of clinical analysis results, he usually experiences a feeling of relief, satisfaction, and reduced anxiety. This preparation, which can be done by the doctor or the health professional reassures the patient, teaches how to deal with the illness and reduces the associated stress and anxiety. In this way, a feeling of security is promoted and the psychological need is satisfied, which is favorable to better treatment adherence and a rapid recovery.

Otherwise, viewing the information in clinical reports can trigger a negative emotional response, promoting an increased need to access health services, rejection of information and poor therapeutic adoption.

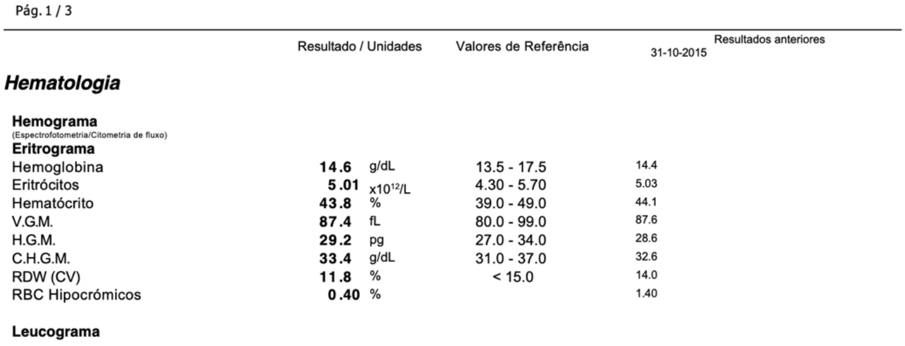
Health information material is released daily in different formats to educate people, focusing on disease prevention and health promotion. However, several authors question whether the content is properly designed with the target audience profile in mind (Dinarés, 2009; Kascak et al., 2013), adding the issue of the lack of credibility of the information available online, which is often not scientifically validated (Espanha et al., 2013).

According to David Sless (2004), the document with medical information is mostly not thought and designed at the highest level, both due to lack of awareness and lack of skills in using appropriate communication methods.

Taking the example of the analytical reports that the general population has access to, we observe that it is designed in exactly the same way for both the health professional and the user, regardless of very different information needs and literacy skills.

The low levels of literacy and numeracy of most users represent a very significant barrier to understanding information, particularly in understanding its ‘reference values’ (Zikmund-Fisher et al., 2014). Through our research (Santos, 2020) we were able to observe that the user expresses difficulty in understanding whether these values are within or outside the reference parameters and even to know what their own reference values are, causing negative emotion when often the information itself is not. For example, the ‘reference values’ indicated in the report may vary according to the age, gender, ethnicity, pathologies of the user, but in general people tend to see the risk associated with their results in a dichotomous way, i.e., values within the reference parameters are “good” and values outside the parameters are “bad”. In this sense, an individual with a chronic illness, deals with an additional barrier of difficulty in understanding and effectively using their results, as the pre-existing ‘reference values’ in the report are not, in fact, a reference for their own results.

According to Scherer (2018), simply replacing the healthy population-based ‘reference values’ with ‘personalized values’ increases the understanding of the information and decreases the need to go to the doctor, at least on an urgent basis. In addition to the message regarding ‘reference values’ not being appropriate for the user, the format in which the reports are presented changes the perception of urgency of accessing a health service. Usually the results are received in a table format (Fig. 1) leading to a wrong perception of the numerical distance to the reference parameters. To correct this problem, Scherer proposes a visual presentation of results in graph format (Fig. 2) compared to table format, that significantly increase understanding of the information and help users distinguish between urgent and non-urgent laboratory results (Scherer et al., 2016).



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	Resultado / Unidades		Valores de Referência	Resultados anteriores 31-10-2015
Hematologia				
Hemograma (Espectrofotometria/Citometria de fluxo)				
Eritrograma				
Hemoglobina	**14.6**	g/dL	13.5 - 17.5	14.4
Eritrócitos	**5.01**	x10^{12}/L	4.30 - 5.70	5.03
Hematócrito	**43.8**	%	39.0 - 49.0	44.1
V.G.M.	**87.4**	fL	80.0 - 99.0	87.6
H.G.M.	**29.2**	pg	27.0 - 34.0	28.6
C.H.G.M.	**33.4**	g/dL	31.0 - 37.0	32.6
RDW (CV)	**11.8**	%	< 15.0	14.0
RBC Hipocrómicos	**0.40**	%		1.40
Leucograma				

Figure 1: Example of clinical analysis report in table format.

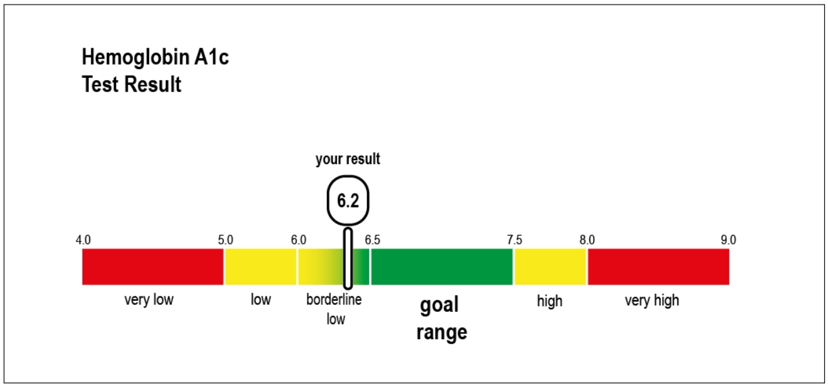

Figure 2: Example of clinical analysis report in graphical format (elaborated by the authors).

Co-Creation as an Inverted Approach to the Hegemonic Model

Nowadays, the access to the health service still happens from a hegemonic model, in which information is designed based on assumptions and not on the real needs of health service users. In this model it is assumed that health is what doctors and hospitals deliver, so information is developed in a conservative and hierarchical approach.

People's participation, on the other hand, has enabled a democratic involvement of all stakeholders in the process of building solutions, which is fundamental in approaches to complex social problems. Co-creation is based on the premise that participation can lead to individual satisfaction (Czepiel, 1990), besides being a differentiating factor (Song & Adams, 1993) or a dominant logic of services (Vargo & Lush, 2008).

In the field of design, the term co-creation initially appears associated with human-centered design or participatory design, and is a form of user integration in the design process, where their capabilities are transformed into resources. The profile - from end users with problems and needs - has changed from 'participants' to 'actors' by bringing local knowledge, specific skills and ideas to the projects. Thus, in this model, users come to be seen as experts.

Participatory design is design "with a special focus on the participation of people in the design process as codesigners" (Ehn, 2008). By placing people at the center of product and service development (Tackara 2005, Papanek 1984, Brown 2009), we are enabling the generation of ideas through the sharing of knowledge and experiences, as well as a better understanding of the user. By repositioning people at the center of the whole process we promote collaborative creativity, increase and extend satisfaction with the service and consequently user loyalty and commitment (Auh et al., 2007). The adoption of codesign can thus contribute to health by increasing the sense of commitment and the possibility of changing behaviors, reinforcing the sense of inclusion and belonging that promote self-awareness and accountability. A method that highlights participatory medicine requires patients and users to participate in tasks traditionally reserved for health 'providers' (Keselman & Smith, 2012), regarding reading and understanding of medical documents. Change streamlined by co-creation, becomes more effective because it is more understandable to those involved, it ensures a space for many to be heard and for diversity and desires (De Koning et al., 2016), opposed to change imposed by a top-down model, which grounds its inquiry in assumptions based on the individual professional's view.

It is also important to note that the engagement space can vary in type of engagement (behavioral, emotional or cognitive), level of engagement (from uninvolved to highly engaged), and in duration (one-time, recurring, or continuous) (Frown et al., 2010).

This involvement can be realized through roundtables, participatory committees, online information sharing, collaborative product development, physical spaces for knowledge exchange, websites, forums, among others.

In health information design, the use of co-creation provides the basis for developing better results, creating a strong sense of ownership of the ideas that result from the process, materializing through experience and contact between the intervening parties and moving away from the simple transaction of data. According to Edgar Dale (1969 cited by Anderson, n.a.) the practice and experience of contact with the object of study, favors knowledge.

CONCLUSION

The knowledge obtained through the messages conveyed by health information should not be done randomly or without the accompaniment of the health professional, otherwise it may create situations of greater anxiety, or even increase an incorrect perception of the urgent need for medical care. Thus, adjusting and personalizing health information allows reducing the inappropriate and repeated dependence on health services.

The traditional model of information still in use today, in which the solution lies only on the side of health professionals, leads to a strong hierarchization of health control and, consequently, to people's individual irresponsibility and passivity. On the contrary, the adoption of a bottom-up methodology, as enabled by participation and co-creation models, puts people and the community at the center of the process, allowing them to have equal control of their information and to realize that health is not only in hospitals and health centers, but rather in their homes, schools, supermarkets, restaurants, etc.

Integrating people into the care of their own health and into processes of co-creation of informational materials, develops trust and willingness for self-control, which in turn can reinforce the adoption of healthy behaviors and the creation of messages that are more challenging and effective.

Furthermore, as demonstrated, an individual who takes control of the management of his or her own health greatly reduces state financial effort. Not feeling the need to go to hospitals and health centers frequently contributes directly to the sustainability of the National Health Service. This situation was recently verified with the pandemic context caused by the new coronavirus, whose impact was felt at a planetary level and with profound consequences for the next generations, both at the health, social and economic levels. This revealed the vulnerability of the health system, both by the reduced number of health professionals and by the lack of solutions to communicate urgently and effectively with an increasingly aging population with inadequate literacy levels.

We can conclude that people's participation in the process of building solutions for health information has two essential advantages: the first one is that the information design is based on people's real and everyday contributions and experiences; and the second advantage is the notion of the user's commitment to that information, showing a greater likelihood of retaining the most important information and applying it to manage their own health.

FUTURE PERPECTIVES

We are concluding this research with the ambition of creating a health information design research process that will allow for the continuous and deeper adoption of these strategies. This includes the development of medical information design in electronic health records and the creation of educational materials that effectively reduce literacy barriers. We also emphasize the importance of making information design more relevant in design education curricula as a means of raising awareness among future designers of the integrative role of this aspect.

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