Design of an Information System for Palliative Care: User Analysis

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Abstract

Objective: *To explore the demographic factors and the level of knowledge related to information and communication technologies of potential users of a palliative care information system.* ***Methods:*** *The Task, User, Representation, Functionality (TURF) framework was applied to characterize potential users (patients and caregivers) of an information system for palliative care in a private clinic in Medellin, Colombia, through a survey.* ***Results:*** *We analyzed 35 patients and 39 caregivers. The majority were women, that lived in urban area and belonged to middle-income socioeconomic stratum. Caregivers, in contrast to patients, are common users of information and communication technologies.* ***Conclusion:*** *An information system should focus on the needs of caregivers, and it would be targeted to subjects facing challenges related to technology adoption; information and communication technologies are interesting and important tools for the improvement of health team.*

Keywords: Telemedicine; Palliative Care; Information Systems.

Introduction

Palliative care (PC) are a set of interventions designed to improve quality of life and control symptoms, while reducing the suffering of patients and caregivers when facing life-threatening illnesses or chronic pain, as well as being a support system to help subjects to maintain an active life, as possible, until death [1].

Given the importance of having PC services that adequately meet people needs, it would be expected that different countries have an integral response in this sense; however, this is not the case, since, on the contrary, there is limited access to them and they are not incorporated into health systems [2].

Identified barriers that patients have to access to the PC include: geographic, economic, and related to infrastructure, among others, that restrict communication between caregivers and health professionals. These types of obstacles contribute to caregiver fatigue, care process deterioration and, finally, to the suffering of the patient and those who care for him [3].

Thus, it is considered that caregivers should assume a greater responsibility in the management of PC. However, in some cases, they do not have the training, vocation nor the time to care. Regardless of these limitations, it has been demonstrated that the participation of families in the care process improves the probability of a dignified death for patients [4]. This finding highlights the importance of designing an information system based on the needs of different users, along with the possibilities of educating them with the knowledge and proper techniques for patient care.

In this sense, the need to train caregivers and patients in information and communication technologies (ICT) in PC was identified, in the context of a health system that is transformed with patient-centered interactive models. These technologies are currently used as tools of health systems and are framed in the concept of e-health, which includes telehealth and telemedicine. Therefore, some solutions are needed that promote the link between caregivers community, health professionals and health system, to help them solve problems effectively, concerning home care, with an appropriate approach to patient needs [4].

Innovative models of telemedicine, driven by advances in ICT, have enabled greater participation of individuals in their own care and encourages to health professionals to identify the worsening of symptoms, support them in their handling, and avoid unnecessary costs for patients in travel times and admissions to hospitalization services [5].

Consequently, the most relevant aspects for nursing practice in this area are the technologies management, the problems identified for their use, the relevant aspects in the symptoms handling and in the follow-up of the disease; ICT allows patient´s autonomy in the monitoring of their disease and care.

This is how telemedicine is an interesting paradigm for nursing, so that it becomes a tool to improve the quality of care. In this sense, the nursing theorist Kristen Swanson, author of the theory of care, has education as the main focus of attention and conceives care as an educational way of getting involved with a user, until he feels the commitment and personal responsibility. In her theory, she proposes five basic principles: being with, maintaining belief, doing for, allowing or enabling, and knowing. In this point, ICT are found with care for the preservation and maintenance of life, where ICT allows the nursing professional to provide education and information to the patient, in order to improve their autonomy, satisfaction and quality of life [7].

Given the above-mentioned scenario, the design of a user-centered information system was proposed, with the intention to assist, monitor and train PC users in a health care institution in the city of Medellin, Colombia. In the user centered design paradigm, one of the most important aspects is the user analysis. User's analysis consists of a process of identification of the types of consumers and the characteristics of each one of them. This step can help to design systems that have the appropriate knowledge and structure of information that match within the users [6]. The aim of this survey was to explore the socio-demographic status, the level of knowledge and management of ICT of PC users.

Methods

The project was approved by the IRB of the School of Health Sciences of the Universidad Pontificia Bolivariana through act 4 of 04/04/2016.

The framework of Task, User, Representation, and Functionality (TURF) is based on theories of user-centered design and evaluation of usability. TURF has been shown to have a number of additional advantages: 1) to describe, explain and predict usability differences, 2) to define, evaluate and measure usability objectively, and 3) to design a built-in usability [6]. In this work, we characterized the users who are part of a PC service in a private clinic in Medellin, through an instrument to perform a characterization of that population and to know what their needs are in PC and in the management of palliative information technology. With the aim of beginning the design of an information system to support the service and provide an added value to patients and caregivers.

One survey was developed for patients and another for caregivers. The first one contained 28 variables and the second 29, including two types of questions: demographic and ICT use. The instrument was developed within the framework of the TURF methodology cited above, and was adapted to the culture and terms of the patients, caregivers and professionals of the institution. The people responsible for applying the instruments were trained and supervised by the Principal Investigator to improve the collection technique.

The selection of patients was made by applying eligibility criteria of the study, as patients entered the center. For their election their participation was not conditioned, each one had the same opportunity to be elected. This selection was made in two health institutions from the city of Medellin, and the instruments were applied between May – September, 2017

Results

A total of 64 surveys were applied: 35 to patients and 39 to caregiver s. In Table 1, is presented the number of variables of the survey.

Table 1. Number of variables per survey

Number of variables per survey		
Type of question	Patient	Caregivers
Sociodemographic variables	7	8
Information and communication technologies Variables	21	21

The instrument focused on the characterization of the people involved in the PC programs, yielding the following results:
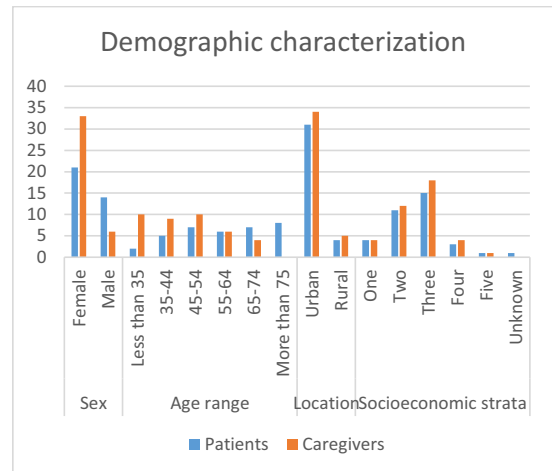

Figure 1. Demographic characterization

Figure 1 shows that 85% of the caregivers and 60% of the patients were women, living in an urban area and belonged to middle-income socio-economic stratum. 23% of patients were older than 75 years, and 51% of caregivers were between 35 to 54 years old.
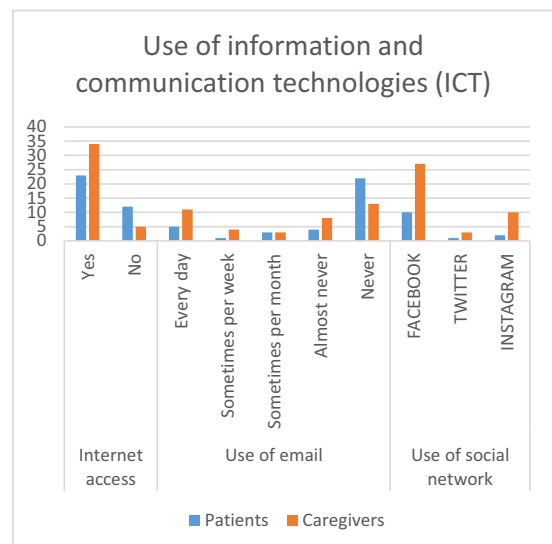

Figure 2. Use of information and communication technologies

Figure 2 shows that caregivers have greater access to the Internet than patients. With reference to the communication channels, we can identify that social networks, like Facebook, is of generalized use for different purposes, and could be a potential channel to provide information, promote informal training of the caregivers, and support PC. The other channel is electronic mail, yet its use is uncommon, neither in patients nor in caregivers.

Discussion

The results of this study showed that 60% of the patients in PC were women, findings consistent with a study carried out in Spain [8], who found that women had a much higher prevalence than men. Regarding age, 43% of patients were older than 65 years, which shows that adults represented almost half of the population where the life cycle ends. However, there were cases in which young adults (35 to 44 years) required this type of care.

The average age of caregivers ranges between 35 to 54 years in 51% of them, being 85% women. With respect to the origin, it was found that 31% of the patients and 34% of the caregivers belonged to the urban area. These findings are similar to those found by Cárdenas et al. [9], who sought to characterize academic and scientific production, as well as to identify strategies and their evolution about social support with the use of ICT for caregivers. In such survey, 14 studies were analyzed, in which a predominant age group of 35 to 65 years (57%) of masculine gender (59%).

Nevertheless, a study carried out by Luxardo et al. in 2009 [10], in which it was proposed to describe the profiles of the caregivers of individual PC, found that the main care activities were developed by women in 84% and that 26% of such was between 38 to 50 years, with 70% living in the urban area. The similarities, in terms of the predominant gender in caregivers are clear. However, there were differences in the age and origin of the caregivers between the two surveys; these differences could be explained because, in the cited study, the sample was selected for convenience, unlike our study in which the selection of caregivers was carried out as patients were hospitalized in health institutions.

One objective of this research was to investigate about patient access to social networks, internet, email and other means that allowed them to access information sent by health professionals and contact them. In this way, it was found that 77% of the patients and 66% of the caregivers declared that they did not have access to the Internet; it was striking that 23% of the patients and 13% of the caregivers reported that they never used the email. These findings are consistent with the research carried out by Cárdenas et al., who made a state of the art of social support in PC and found that the most widely used technology was the Internet, with online questionnaires, email, software, training, communities, discussions and chat, with the online questionnaire being the most used [9].

A clear observation of this study was the importance of designing an information system based on the caregivers´ needs and the possibilities of educating them with adequate knowledge and techniques for care. It is consistent with an investigation carried out in South Australia in 2014, whose objective was to conduct a telehealth development model, which allowed a better interaction and exchange among participants, a greater use and clinical value of a PC prototype [11].

While conducting the survey, there were some limitations with the approval of data collection in an institution of PC, due to administrative barriers, which delayed the schedule of the study. Additionally, the vulnerability of the patients secondary to terminal illness and acute pain at the time of the research, which made it difficult.

Conclusions

Taking into consideration the use of information and communication technologies, age and internet access of people involved in palliative care, an information system should focus on the needs of caregivers, finding that should be supported by the following analyses according to TURF framework.

One of the communication channels employed by patients and caregivers were the social networks, which indicates the importance of an information system that uses this social network as a channel of information and dissemination.

Acknowledgements

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