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# THE IMPORTANCE OF INFORMATION AND COMMUNICATION TECHNOLOGIES (ICT) TO PROMOTE INFORMATION, SELF-CARE AND EMPOWERMENT AMONG PATIENTS WITH CHRONIC ILLNESSES

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## Abstract

In the last decades, there has been some technical-scientific advances in the healthcare domain, enabling us to live longer. This reality is particularly important for people suffering from chronic diseases, because they have to find good ways to manage their limitations and healthcare condition. Therefore, self-care promotion is one of the biggest challenges of healthcare, particularly for nurses. At the same time, technologies are increasingly used methods by patients to search for information and knowledge about their diseases. With this paper, we intend to verify in what extent does Information and Communication Technologies (ICT) help patients with chronic diseases to promote their self-care and to manage their condition. So, we conducted a systematic literature review, focused in following databases: Medeline, Cinahl, PubMed. The key-words used in this research were: chronic disease, self-care, self-management and information systems.

We found results from previous works evidencing that patients with chronic diseases resort online information sources (considered reliable), to acquire information that help their self-efficacy and self-management of health condition. The communication or collaborative tools used are primarily the email, discussion forus, blogs and social media. Online programs of self-management of chronic illness also contribute to a faster communication stream between patients and health care professionals, in order to allow feedback and social support, having a positive impact in patients' behaviours, in terms of their adherence and therapeutic management, and also improving health care demand. Thus, we may recognise that the use of ICT, through various types of media (smartphone, tablet, notebook, ...) not only promotes health education, self-care and empowerment, but also facilitates the communication between patient and health care professionals. We highlight that ICT is a relevant contribution to chronic diseases' patients, facilitating their lives at different levels, and in particular, providing adequate tools to deal with their health condition.

Key-words: Chronic-disease; Self-care; Self-management; Information.

## 1 INTRODUCTION

Chronic noncommunicable diseases such as Chronic Obstructive Pulmonary disease (COPD), type 2 Diabetes, Arthritis and Heart failure, are the leading causes of disability, morbidity and mortality that causes major health's problems and pressure on the sustainability of worldwide health care systems [1]. World Health Organization estimates that by 2020 more than half of the causes of death will be related to chronic diseases [2]. Due to technological evolution in the health department, average life expectancy has been steadily increasing, which leads to people living for more years with one or many chronic diseases, whose repercussions compromise selfcare and increases vulnerability. Self care is considered by Orem [3] as the capacity each person has to manage their own health throughout life. Underlying this concept is self-management, defined as the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" [4], [5]. Besides being related with the patients' rights to decide on their care, self-management also directs to the ability for action, not only related to decision making capability, but also with the functional and physiological aspects of it. Self-management of a chronic disease is often a

lifetime task. This requires the involvement and active participation of the patient in his own health process like the family to accrue the knowledge, confidence and skills to manage his condition. [6]. In this sense, nursing care should be adjusted to advocate individual capacities of patients, promoting personal autonomy and empowerment. Encouraging empowerment is helping people to use and enhance their own ability to manage their health condition [7]. This entire process requires self-management of oneself, making health care professionals and patients be actively involve, implying patients centered care. Patients centered care, which encompass self-care and self-management, is a fundamental concern for nursing, very important and essential to the prevention and management of chronic diseases [8].

Self-care and empowerment are considered key principles in chronic disease management and some authors suggest that future health systems' sustainability will mainly depend on people's ability to self-manage their conditions [2], [9]. The ultimate goal of chronic diseases care management is to optimize self-care in order to reduce mortality, morbidity and health care costs [10].

Information and Communication Technologies (ICT) into nursing care has brought many opportunities for self-care [11], as it can be used as a powerful away for promoting a healthy lifestyle and for increasing the understanding about the condition [10]. However, to be effective in empowering patients' self-awareness and engagement the ICT must be useful to their own specific needs of health [12]. New opportunities exist as a result of recents advances in home-based wireless devices, apps and wearables enabling health delivery systems to monitor disease in real time. These technologies provide a framework for patient engagement and a new model of care delivery utilizing integrated practice units both very important to navigate the healthcare needs of the 21st century [12].

From previous studies we know that ICT contributes positively to health care for patients with a chronic illness, realizing increased patient-provider communication, positive impact on behaviour change, improved therapy adherence, and cost reductions [10].

When using ICT in health care, the partnership between the patient and the professionals is crucial, where the self-management means that the people with chronic diseases become the managers of their own condition and the health care professionals are taken for "consultors" supporting them in these roll. ICT is considered an important facilitator of such partnerships but, above all, it does not only helps patients and their families to increase their knowledge and trust to manage their condition [6].

The aim of the study was to verify in what extent ICT helps patients with chronic diseases to promote their self-care and self-management in their condition. We will analyze the results of a systematic literature review, according to the concepts of self-care, self-management and empowerment.

## 2 METHODOLOGY

It was performed a systematic literature review, in a exploratory way, structured and strictly compiled interventions of nursing that contribute for a practice based on the evidence. According to the problems in study and for a wider understanding of this phenomenon, the following question follows the criteria of the PICO format [13]: In patients with chronic diseases (population) such as ICTs' (intervention) help promote the self-care and self-management of their condition (outcome)? It was performed a research in the electronic data bases: CINAHL, MEDELINE and PUBMED. The boolean descriptors<sup>1</sup> and operators were used with the following guidance: To obtain eligible data in view of the question of the investigation and objective of the study, there were established inclusive and exclusive criteria (cf. Table 1).

*Table 1. Criteria for Inclusion and Exclusion of the articles in the study*

Criteria for Inclusion	Criteria for Exclusion
<ul style="list-style-type: none"> <li>• Studies targeting adults and aging people with chronic disease;</li> <li>• Referring interventions in the scope of promoting self-care and self-management using digital health systems.</li> </ul>	<ul style="list-style-type: none"> <li>• With unclear methodology;</li> <li>• No correlation with the object of study;</li> <li>• Repeated in different databases</li> <li>• Written in English;</li> <li>• Not available in full text;</li> <li>• Published more than 5 years ago.</li> </ul>

<sup>1</sup> Concepts verified in the international base MeSHBrowser, in: <http://www.nlm.nih.gov/mesh/MBrowser.html>

The research was fulfilled in February 2018 and it was identified in total ninety eight (98) articles. After filtration the articles available in integral text, written in English, published in the last five years and not repeated in the different data bases, thirty nine (39) of the articles were excluded. These selection resulted in fifty nine (59) articles, which were analyzed by two independent reviewers following the inclusion and exclusion criteria, ended up being selected five (5) studies. The articles were analyzed regarding their evidence level, using the guidances that suggest 5 levels<sup>2</sup>.

Of the selected articles, three are randomized studies controlled with evidence level 1b and two studies quantified with a evidence 4 level. The methodology followed is shown in the figure 1.

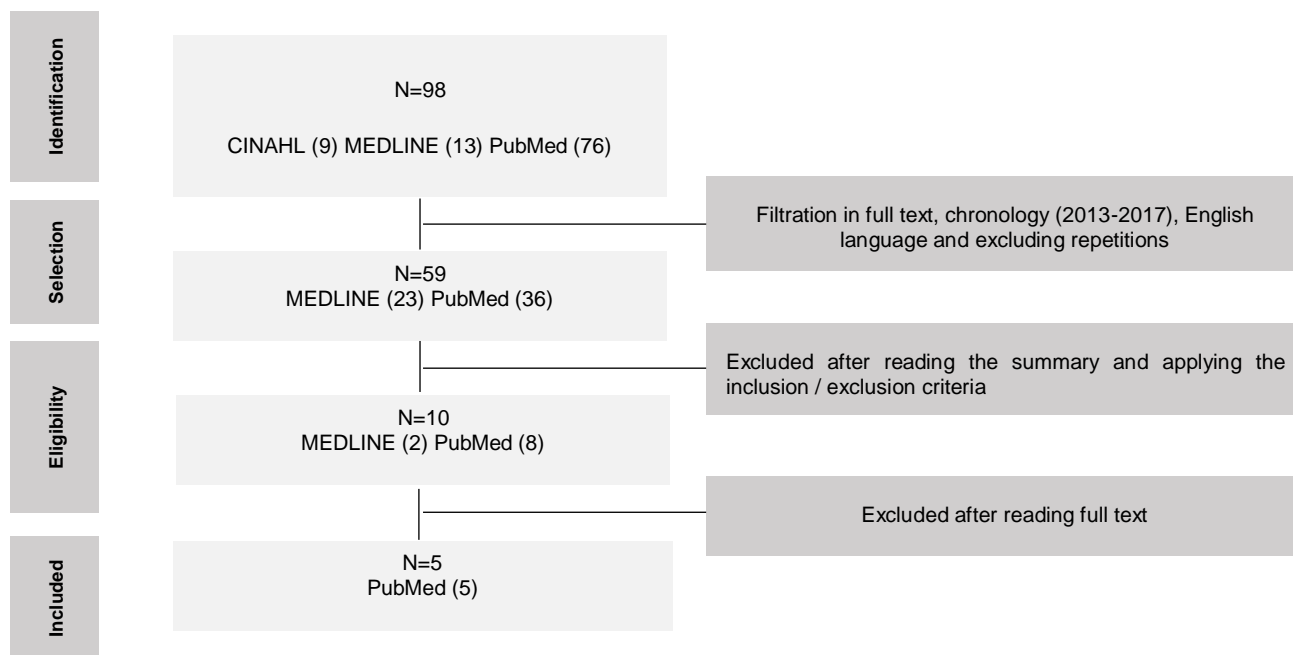


Figure 1. Research Filtering Method Performed

### 3 RESULTS

We verified that the ICT's were identical in the different studies, the web intervention provided throughout the informative platforms and of registration as well as of e-learning where the more evidenced. It was possible to identify that the ICT's have positive effects in the patients with chronic diseases, which was verified that these have effects in the promotion of self-care and in self-management of their health [15], [16], [17], [18], [19]. One of the results of the studies was the improvement of the overall increase of the patient's health status, linked with a bigger knowledge and information about the control of symptoms and therapeutic regime [16] that allowed a better self-management of their condition, decreasing the visits to the hospital [15]. It was also verified that the interventions based in these ICT's allow an increase of adhesion of behaviours associated to healthy lifestyles such as: diet, physical exercise, smoking cessation that have positive effects specially in patients with diabetes, DPOC and heart diseases [15], [17], [19]. One randomised study fulfilled in

<sup>2</sup> Level of evidence 1a comes from Systematic Reviews (SR) (with homogeneity) of Randomized Control Trials(RCT), 1b individual RCT (with narrow Confidence Interval), 2a SR (with homogeneity\*) of cohort studies, 2b Individual cohort study (including low quality RCT), 3a SR (with homogeneity\*) of case-control, 3b Individual Case-Control Studys, 4 Case-series (and poor quality cohort and case-control studies) e 5 Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles" [14] Howick J, Chalmers I, Glasziou P, Greenhalgh T, Heneghan C, Liberati A, et al. The 2011 Oxford CEBM Levels of Evidence (Introductory Document) 2011. Available from: Oxford Centre of Evidence Based Medicine [serial online, accessed 7/13/13].

the USA, proved that the patients with diabetes that have support through a website improve their engagement in self-management of their disease [20]. On the other side, the ICT's have proved a close relationship between the patients and the health care professionals. In the study analyzes [15], [18] it was verified that the patients with chronic diseases that has access to these digital tools feel more supported, what reduces their stress and anxiety.

Table 2. Main Results of Systematic Review.

Autores/year/setting	Participants	Interventions	Findings
Farmer, Willians, Velardo, Ahmar, Yu, Rutter, Jones, Willians, Heneghan, Price, Hardinge & Tarassenko (2017) Reino Unido	Patients with COPD	Internet-linked platform implemented on a low-cost tablet computer	Improvement of health status Reduce recurrence to outpatients Reduces anxiety
Murray, Sweeting, Dack, Pal, Modrow, Hudda, Li, Ross, Alkhalidi, Barnard, Farmer, Michie, Yardley, maio, Parrott, Stevenson, Knox, Patterson (2017) Reino Unido	Patients with Diabetes Mellitus Type 2	Web-based selfmanagement programme or a simple, text-based website containing basic information only	Improvement of disease control (glycemic levels) Stress reduction
Pfaeffili Dale,Whittaker, Jiang, Stewart, Rolleston & Maddison (2015) Nova Zelândia	Patients with Coronary Disease	Text messages and a supporting website	Improvement in adherence to behaviors related to healthy lifestyles
Hoving, Zoer, Meer, Straaten, Logtenberg-Rutten, Kraakput, Vries, Tak, Sluiter, Frins-Dresen(2014) Holanda	Patients with Reumatoid Arthritis	Internet e-health	Emotional support Improved self-efficacy and self-management of the disease
Safdari, Jafarpour, Mokhtaran, Naderi (2017) Teerão/Irão	Patients with Heart Failure	System Java technologies, Android, XML, SQLite, MVC	Improved self-care and quality of life Facilitated the hospital-home transition

Patients who believe they have a responsibility to take an active role in making decisions about their health are central to effective chronic self-management [21]. The ICT are being introduced to support self-management of chronic disease, involves integrating the patients as a full-fledged partnership between patients and health care professionals in ICT enable person-centred care is lacking.

We also verified that ICT promote self-efficacy in patients with rheumatic disease [18], which is reflected in increased confidence and ability to perform daily activities, with reduced pain and increased functional capacity [22]. The majority of previous studies with ICT have demonstrated positive changes in health status, and sometimes increase quality of life in patients with crhonic diseases [22] which corroborates a study that we selected [19]. Also, describing that ICT increased the opportunities to patients for accessing information that disease's self-management [15], [16], [17], [18], [19], the management of symptoms, the identification of exacerbations and therapeutic management [15], [16], [19].

This systematic literature review evidence that ICT and a information provided by health care professionals help patients to acquire skills involving patients and makes decisions related to their treatment, with the aim of increasing the self-care and well-being [23] that contribute to empowerment.

## 4 CONCLUSIONS

Nowadays, we think that the effectiveness of ICT interventions for patients with chronic disease is a significant challenge for patients and health care professionals too. ICT as an important away to facilitate a partnership between patient and professional and helps a successful self-management of chronic diseases. These allow patients handle their life with some degree of autonomy despite their condition and to feel healthy despite their limitation [24].

In the different studies we identified that ICT contributes to patients increase their knowledge about their health leading to: adopt healthy lifestyles and behaviour changes, reduce stress and anxiety, increase self-efficacy and self-management which decreases the recurrence of consultations, improving overall health status. ITC also may help train chronically ill patients to make informed decisions and solve daily self-management problems, as diet, physical activity, medication adherence and smoking cessation.

We can expect specialized patient-centered websites to arise in response to specific chronic disease information need. So, patients become their own principal caregivers, and health care professional are seen as “consultants” supporting them in this role [6]. It's not always like that, ICT applications do not take into account the partnership between patients and health care professionals and are focused on only one of these parties rather than considering both [25]. This lack of consideration increases the risk that this application is not useful and do not help patients in promoting self-care by making them even more vulnerable. Another limitation in the use of ICT is the lack of knowledge of patients, especially the elderly to use these tools as well as difficulty in acquiring them and technical difficulties such as lack of access to the Internet that can prevent the use of ICT.

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