Chapter 2 Intra-Hospital Virtual Communities and Well-Being of Cancer Patients: Impact of Features on Healthcare Relationships

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ABSTRACT

The use of social media in health is emerging as a means of bringing the various actors together with several benefits. In the specific case of cancer disease, these tools can help patients to improve their psychological well-being and their outcomes. As cancer is the cause of a quarter of deaths in Portugal, it is a pressing issue to understand which tools and information both patients and health professionals find most useful to build effective health social media. It was observed that there is a latent need for an oncology social environment, allowing greater well-being for patients and strengthening their relationship with health professionals and institutions, constituting an asset to the services provided. This chapter fills a gap in the bibliography by bringing together the views of both patients and health professionals from several areas, in close collaboration with the Francisco Gentil Portuguese Oncology Institute of Porto, E.P.E.

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1. INTRODUCTION

According to the 2018 Portugal's Health Portrait, prepared by the Ministry of Health, cancer is the second leading cause of death in Portugal, accounting for about 25% of deaths that year.

Cancer is a life-threatening disease, and it is not always easy for the patient to maintain confidence and positive thinking about the outcome of their condition. However, as Erfani et al. (2017) highlight, a patient's optimism and the social support they receive are critical to their psychological well-being which, in turn, contributes positively to the likelihood of surviving the cancer (Chida & Steptoe, 2008).

The use of social media in health emerges as a means of bringing the various actors together with several benefits. For example, the use of social media allows patients to get more information about their disease and the treatment that they are undergoing (Al-Muhtadi et al., 2019), as well as interact with other patients and share experiences, knowledge, and advice (Gupta et al., 2020; Johansson et al., 2021). In addition to this, social media can impact the relationship with healthcare professionals, opening doors to greater personalization of care, and strengthening the doctor-patient relationship (Rajkomar et al., 2019). This last point became quite visible as the pandemic progressed, namely in the Facebook social network groups aimed at clarifying doubts about the disease caused by the SARS-COV2 virus. In these groups, health professionals played a pivotal role, acting as sensitizers and reassurers for the thousands of group members (Furstrand et al., 2021). However, the use of social media is not without risk (Benetoli et al., 2018; Eysenbach, 2003; Johansson et al., 2021; Schweizer et al., 2006) and its structure should be suitable for the users' needs (Fu et al., 2020).

Thus, this chapter aims to clarify the functionalities and characteristics seen as most relevant, by patients and by health professionals, of an oncology virtual community, which leads to forming the research question of this chapter: "What are the functionalities of virtual communities and their most important features to support cancer patients and what kind of information do health professionals consider important and want to obtain in virtual communities?".

By bringing health professionals' views on these platforms into the study, this chapter bridges a gap in the literature (Johansson et al., 2021). Data were collected in close collaboration with the Francisco Gentil Portuguese Oncology Institute of Porto, E.P.E. (hereinafter IPO Porto), using a mixed methodology, with patients and health professionals of this institution. Since it was carried out within an health institution and with its support, data collection followed a rigorous assessment process, namely by the Data Protection Officer and the Ethics Committee for Health, with a favorable opinion from them and the Board of Directors of IPO Porto.

The provision of this social medium by the healthcare institution, especially with the features and information most sought after by users, could be a further asset to the health service provided (Li et al., 2018). This is an important factor in the evaluation of health services in Portugal (pp 43-47 of the Standards Manual for Health Care Facilities/Hospital Centers) and one of the areas of action of the Portuguese National Strategy for Quality in Health, placing the patient at the center of the service provided, as a customer of the institution.

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