ABSTRACT

Taking the perspective of the individual, this thesis addresses the increasing use of Internet by patients seeking information and connections to cope with a new life situation caused by chronic illness. The main objective is to understand and conceptualize this use of the Internet. A qualitative study of 7 patient associations, 15 patient self-help groups and 18 individual patients comprise the empirical data. Parkinson’s disease, Multiple Sclerosis, Whiplash injury, and Prostate cancer exemplify medical conditions represented in the studies. By drawing on coping theory, further developed by means of theoretical constructs related to studies on information behaviour and online interaction, the work adds a perspective on information technology use related to psychological reasoning about how individuals manage stressful situations like facing chronic illness. The findings show that patients’ use of the Internet can be understood as means to cope with a difficult life situation, the particular problem (the illness), and the related emotions. The main implications from this study for the development of Internet use in the patient-healthcare relationship suggest that the design should consider patients’ requirements for flexible and personalized Internet solutions, development of spaces for online dialogues, general as well as specific medical information, and to provide professional online guidance to relevant and reliable medical information. For healthcare practice, the main implications are to increase healthcare’s Internet awareness and online participation. Additional implications concern the development of well-informed patients, acting as both users and producers of medical information, putting additional technological demands on healthcare’s Internet use, and strengthening their position to challenge the medical expertise. Further, coping online accentuates the issues of digital/medical divide where some individuals strong on resources get access to healthcare on different conditions than others.

Keywords: Internet, users, patients, medical information, self-help, healthcare practice