Information as a tool for empowering patients coping with chronic diseases / Sharon Naveh

Abstract

When an individual encounters a crisis, numerous questions arise regarding the implications of their new situation and its impact on their life. These questions drive them to seek relevant information, allowing them to bridge any knowledge gaps, make sense of their newly introduced circumstances, and regain a sense of control. The diagnosis of an incurable chronic illness constitutes a significant life crisis, abruptly shifting the patient from a well-familiar routine to a strange and threatening reality. The knowledge that they now have a chronic illness fundamentally disrupts their entire worldview, transforming them from a healthy person into a "patient" - someone requiring medical care and forced to adjust their lifestyle to the limitations associated with this new health reality. This adaptation process begins even in the early stages of medical evaluation, when suspicions arise, and the individual undergoes various tests. Access to reliable, available, and relevant information can help the patient navigate these uncertainties, manage their concerns, and cultivate the internal resilience necessary for maintaining a stable lifestyle despite their illness.

This study aims to explore the role of information in the lives of patients coping with chronic illnesses and its contribution to regaining control and fostering a sense of empowerment. It focuses on identifying the unique information needs of these patients, as reflected in their information behavior patterns, to facilitate their acceptance of their new medical condition, enhance their self-efficacy, and support their coping strategies. The research employs a mixed-methods approach, integrating both quantitative and qualitative methodologies, utilizing the "Sense-Making" model, Transition Theory, and Self-efficacy Theory. The study follows an "Explanatory Sequential Design", initially conducting quantitative analysis followed by qualitative exploration, allowing for an in-depth understanding of patients' information needs and providing comprehensive answers to the research questions and hypotheses.

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The study examines patients diagnosed with one of the following chronic illnesses: Multiple Sclerosis or Inflammatory Bowel Diseases (Crohn's disease or Ulcerative Colitis). This multi-phase research consists of three main stages. The first stage investigates the role of information in patients' coping mechanisms through a quantitative analysis focusing on three aspects: information-seeking behavior, social support, and health empowerment. This was conducted via a survey completed by the study population (N=161). The second stage, based on findings from the quantitative research, involved a qualitative analysis of semi-structured interviews with patients (N=16), further examining these three aspects. The third stage analyzed online messages posted in forums on the Israeli health-related website "Camoni" (N=200, excluding associated response threads) to enrich research insights regarding the nature of information that patients require when dealing with their health condition.

This study yielded several key insights. First, information is a crucial tool for patients in managing their health condition, serving as a valuable component in achieving health empowerment, despite the challenges of chronic illness. However, findings indicate significant variability in patients' information behavior patterns and their adoption of information practices, influenced by socio-demographic characteristics and personal circumstances. Given the vital role of information in effective disease management, it is essential to deepen our understanding of how patients seek, process, and share information.

An additional key insight highlights the importance of emotional and social support for patients. As stated, the diagnosis of a chronic illness marks a pivotal life transition, instantly reclassifying an individual as a "patient." Given that a person is a complex entity composed of both body and soul, understanding the impact of such a traumatic transition necessitates consideration not only of the physical aspects of the illness and its symptoms, but also of the wide range of emotions that arise in response to this change in their health condition. Many patients experience emotional distress even before facing the physical challenges of the disease. This study's analysis of online posted messages revealed that most of these messages (58%) discussed emotional and social support topics. This underscores the essential role of emotional and social support in shaping a holistic therapeutic approach. The significance of such support is particularly evident in patients' use of the internet, especially in dedicated online discussion platforms. These groups

provide patients with unique opportunities that are not available through in-person meetings or medical consultations, offering a dedicated and highly suited space for emotional and social support.

A third key insight from this study is the significant contribution of health empowerment to the patients' ability to cope with their illness and its consequences. Findings suggest that patients who achieve health empowerment not only manage to accept their illness, but also to find new meaning in their health condition, gaining a sense of control over their situation and acquiring confidence in their ability to maintain full and normal lives, despite the disease. However, the journey from illness diagnosis to empowerment is neither immediate nor guaranteed, as patients undergo an internal process that is often challenging and complex. This study's examination of patients' information practices and emotional responses sheds light on the difficulties and intricacies of this journey. Nonetheless, achieving health empowerment is highly beneficial in helping patients navigate the challenges of chronic illness.

This research proposes a model titled "Information-Based Coping with Chronic Illness", which illustrates the relationship between patients' information behavior and their progression along the disease timeline, similar the Kübler-Ross's model. The findings indicate a significant correlation between patients' information needs, their information behavior patterns, and the specific stage of illness they are experiencing. The study reveals that information behavior evolves as patients transition from early symptoms through medical evaluation, diagnosis, acceptance, and ultimately, managing their illness's constraints and, in some case, achieving health empowerment. Importantly, the disease timeline is not linear or fixed; patients may revisit earlier stages due to health deterioration, reintroducing uncertainty and distress. Consequently, they often revert to information-seeking practices characteristic of earlier phases. These recurring information behaviors align with the emotional stages of grief described in Kübler-Ross's model, illustrating the profound psychological process patients undergo when adapting to their chronic illness condition.

This study contributes valuable insights into how information behaviors influence chronic illness adaptation and highlights the need for tailored information strategies to support patients' evolving needs throughout their medical journey.

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