

Empowering fibromyalgia patients using information / Ya'ara Kaniyas

Abstract

The present research explores the way in which fibromyalgia patients in Israel can be empowered by using information. To accomplish this aim, we used a Mixed Methods design that combines both quantitative and qualitative methods. The specific model, which we used, is called "The Exploratory Design". At first, we conducted 20 in depth interviews with diagnosed fibromyalgia patients in different stages of the illness. These interviews were analyzed in a qualitative method. A group, composed of 100 fibromyalgia patients, was given a questionnaire developed upon the earlier qualitative analyses. This way, we were able to validate our conclusions in a wide distribution using a quantitative method. The study uses concepts taken from the theories of empowerment, psychology and information behaviors.

Previous research in the field shows that the chronically ill experience a decrease in their sense of control regarding their health condition from the moment the diagnosis is given. An empowering process is essential.

It enables the patients to believe they can cope with the disease and thus raise the level of their self-efficacy and restore their sense of control. Patients undergoing a process of empowerment, tend to cope better with the disease and respond positively to the treatment by taking an active position. Empowerment is a gradual process and it accommodates every patient according to his/ her pace of coping with the disease. This process is mainly based on the way patients use the information they have acquired from personal experience in dealing with the disease and external information acquired from various sources. Beneficial information, regarding fibromyalgia patients, bridges the gaps created due to its absence.

The purpose of this research was to examine fibromyalgia patient's information needs during the various stages of coping with illness, to examine the connection between duration of the disease in the patients and their need of information, and to explore the sources of information preferred by patients and their satisfaction from the information provided.

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