Information needs and information behavior of patients with rare chronic diseases in Croatia

Synopsis of the doctoral thesis

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Aim and purpose of the research

This research aims to identify:
1. information needs of patients with rare chronic diseases in Croatia
2. their information sources usage and preferences
3. their information seeking patterns
4. important factors that influence 1, 2 and 3.

Purpose of the study is to:
1. suggest an appropriate theoretical and methodological approaches to studying information needs and information seeking behavior of patients with rare chronic diseases
2. provide guidance for improving information provision to patients with rare chronic diseases in Croatia.
Why is this problem important to investigate?

1. Rare chronic diseases are usually:
   - medically rather complex
   - chronic and degenerative
   - generally poorly researched
   - their treatment is prolonged and complex
   - treatment requires the active involvement of patients themselves
   - impact of the disease on individuals daily life is multilayered

2. Rare chronic diseases result in information needs and information seeking behavior that are:
   - a complex phenomenon
   - an important element of coping
   - generally poorly explored
   - not explored at all in Croatia.
3. Information provision for patients with rare chronic diseases in Croatia is characterized by:

- No formal form of information provision and patient education
- A small number of associations of patients with rare chronic diseases and their uneven geographical distribution across Croatia
- Patient information leaflets (PILs) for rare chronic diseases generally do not exist or are not in general circulation
- There is a lack of information sources about these diseases on the Internet in Croatian language

Therefore, how do patients suffering from rare chronic diseases that lack formal social and informational support mechanisms, in the “unrich” information environment, seek information?
Previous work

- Late 1980s - first studies of health information seeking
- From the mid of 1990s - increasing number of studies of health information seeking in different disciplines (medicine and ICS!)
- Central issue - preferred information channels and sources, relationship between information and the source
- The most common theoretical basis - stress/coping theory (Lazarus, Folkman, 1984) and monitoring and blunting (Miller, S. M., 1987)
- Studies of information needs and information seeking behavior of patients with common chronic diseases – the most common
  - cervical cancer, breast cancer, heart disease and diseases of the spine etc. (Looking for information, Case, D. O., 2007)
Studies of information needs and behavior of patients with rare chronic diseases

- Study of the World Wide Web as a medium for delivery of systemic lupus erythematosus patient information
- A patient-oriented website can have a positive effect on disease knowledge

- Study of the role of an Internet-based group for people who have a rare autoimmune liver disease
- The Internet offers an opportunity for those with rare diseases to connect with, learn from, and provide support to others having similar experiences.
- Patients’ judgements on being ill and being rare
- Emphasized need for non-medical information related to coping with the disease in everyday life, action-oriented and ability-related information, significant role of patient groups

Waldron, N. et al., 2011.
- Study of the information needs of patients newly diagnosed with systemic lupus erythematosus
- Information and support currently provided at diagnosis is inadequate for their needs, preference for detailed information, provided through a variety of formats, strong preference for informational support from medical professionals
Theory or model that will guide the research

CMIS - Comprehensive Model of Information Seeking

Factors that motivate and determine information seeking

Direct experience with the disease

Personal significance of disease-related information

Beliefs about facts and self-efficacy

ANTECEDENTS

Background Factors

Demographics

Experience

Personal Relevance Factors

Salience

Beliefs

INFORMATION CARRIER FACTORS

Characteristics

Utilities

INFORMATION SEEKING ACTIONS

Perceptions of their credibility and understandability

Action

Conscious choices among channels and sources

Usefulness with regard to the specific needs of the individual

Model was developed by studying information behavior of cancer patients (Johnson; Meischke, 1993.)
Specific research questions

Q1: What are the information needs of patients with rare chronic diseases?

Q2: What are the obstacles to satisfying information needs patients with rare chronic diseases in Croatia face?

Q3: What information sources do they use for health information?

Q4: What is the role of different sources of information in acquiring cognitive and affective health information for patients with rare chronic diseases?

Q5: Is there a relationship between different forms of information behavior and health behavior?

Q6: What is the relationship between different demographic and socioeconomic factors and information needs and information seeking of these patients?
Methodology

- Quantitative and qualitative methods:
  - questionnaire – demographic and socioeconomic factors, information sources usage, information needs and information seeking behavior
  - semi-structured interviews – obstacles to satisfying information needs, patients suggestions regarding improving information provision

- Respondents:
  - adult patients suffering from rare chronic diseases on the sample of patients with inflammatory diseases of connective tissue - collagenosis
Stages of the research plan

1. stage - questionnaire survey of patients suffering from collagenosis at the:
   - departments of clinical immunology in hospitals in Osijek, Zagreb and Rijeka
   - associations of patients in Split and Zagreb
   - online forums for systemic lupus erythematosus (SLE) and scleroderma

2. stage - semi-structured interviews with respondents

3. stage - analysis of collected data
   - Data collected by questionnaires will be processed by SPSS by the laws of descriptive statistics.
   - Interviews will be transcribed and analyzed by descriptive methods.
The expected contribution of the research

- Critical evaluation of existing theoretical and methodological approaches in studying information behavior of patients with rare chronic diseases.
- Formation of appropriate theoretical and methodological approaches.
- Understanding the information needs and information seeking behavior of patients with rare chronic diseases and important factors that influence them.
- Providing guidance for improving information provision to patients with rare chronic diseases in Croatia.