

# PERCEPTIONS OF DISEASE AND ILLNESS AMONG FREQUENT ATTENDERS OF PUBLIC HEALTH CLINICS IN ISRAEL

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## Abstract

*Background:* The significance of these disease representations is their contribution to understanding the meaning and definition one ascribes to the illness, as well as how one copes with and adjusts to it (Leventhal et al. 1980). Frequent attenders consume a great deal of medical care and create a burden for the treating physician and the healthcare system (Bass and May 2002). *Methodology:* The purposes of the study were to characterize the perception of disease and illness among frequent attenders and to understand the meaning of sense of health as perceived by frequent attenders. In this paper will present the findings of ten semi-structured in-depth interviews. *Results:* The research findings show how perceptions of disease and illness, as well as deficient coping with illness among frequent attenders, constitute an element that disrupts normal life and requires considerable use of healthcare services due to the resulting sense of discomfort and pressure. *Conclusions:* Use of an intervention model that enhances one's mental resilience appears to be a possible solution for reducing the phenomenon of frequent attenders.

**Keywords:** disease, illness, frequent attenders, Basic-Ph Model, primary care

## Résumé

*Encadrement de la recherche scientifique dans le contexte:* Les représentations de l'importance de ces maladies est leur contribution à comprendre le sens et la définition de l'attribut de la maladie et la façon dont ils font face et adapter (Leventhal et al. 1980). Les participants fréquents prennent beaucoup de services médicaux et le rendent plus difficile pour le personnel et le système médical. (Bass et May 2002). *Méthodologie:* Le but de cette étude était de caractériser la perception de la maladie et de la maladie chez les participants fréquents et de comprendre comment ils perçoivent la signification de l'état de santé. Dans cet article, nous présentons les résultats de dix entretiens semi-structurés. *Résultats:* La recherche montre comment la perception de la maladie et la carence à faire face à une maladie fréquente chez les participants, un élément qui perturbe la vie normale et nécessitent une utilisation considérable des services de santé en raison de l'inconfort sens et de la pression. *Conclusion:* L'utilisation d'un modèle d'intervention pour améliorer la

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résilience mentale semble être une solution possible pour réduire le phénomène de participation fréquente.

**Mots clés:** maladies, participants fréquents, modèle de base - Ph, soins primaires

### **Rezumat**

*Încadrarea Cercetării în Contextul Științific:* Semnificația reprezentărilor acestor boli este contribuția lor în a înțelege sensul și definiția pe care o atribuim bolii, precum și a modului în care le facem față și ne adaptăm (Leventhal et al. 1980). Participanții frecvenți acaparează foarte multe servicii medicale și îngreunează personalul și sistemul medical. (Bass & May 2002). *Metodologie:* Scopul acestui studiu au fost să caracterizeze percepția asupra bolii și a stării de rău printre participanții frecvenți și să înțeleagă cum aceștia percep sensul stării de sănătate. În acest articol prezentăm rezultatele a zece interviuri în profunzime semi-structurate. *Rezultate:* Rezultatele cercetării arată cum percepțiile asupra bolii, precum și deficiența în a face față bolilor în rândul participanților frecvenți, constituie un element care perturbă viața normală și necesită o utilizare considerabilă a serviciilor medicale datorită sensului de disconfort și a presiunii. *Concluzie:* Folosirea a unui model de intervenție, care să îmbunătățească reziliența psihică, pare a fi o posibilă soluție pentru reducerea fenomenului de participare frecventă.

**Cuvinte cheie:** boli, participanți frecvenți, modelul Basic - Ph, îngrijire primară

## **1. Introduction**

The terms disease, illness, and ill health are often used in the same context although each has a different meaning. Disease means discomfort, trouble. At present, the term disease is attributed to an objective state of ill health confirmed by tests. Disease is the existence of a detectable physical pathology or abnormality. A disease can be the result of exogenous or endogenous factors. Illness is the subjective experience of loss of health. One way that illness receives meaning is through the story we tell about how we became ill. The process of giving meaning to illness is manifested in the question: Why me?

Disease and illness are not identical, although they are highly compatible. For example, one can be diagnosed as having cancer by a test even in the absence of any previous symptoms, i.e., a person can be diagnosed with cancer even if he or she did not report any illness.

When one reports symptoms and is diagnosed as being ill by means of blood tests, disease and illness are congruent. In such a situation, the term ill health is used. Therefore, ill health is an overall term used to encompass disease and illness (Naidoo and Wills, 2009).

Many sociologists see health and disease as a social entity. Health and disease are not an objective reality that awaits confirmation of the medical sciences, rather they are acts that are formed and actively that can be negotiated by normal people (Naidoo and Wills, 2009). Another aspect is illness perception, which too is formed by one's cultural and social environment and by one's experience with disease and treatment. Illness perception is associated with treatment consequences, which include adherence to treatment, functional recovery, coping, and self management (Cabassa et al., 2008). The current paper presents the findings of a qualitative study aimed at clarifying the illness perception of frequent attenders. This clarification will contribute to existing knowledge on frequent attenders and may help achieve better management of the visits of such patients to primary health clinics.

## 2. Literature review

This chapter deals with the factors that affect one's illness perception and, consequently, patients' consumer behavior with regard to the health services. In this chapter we will discuss the effect of the cognitive representations, the patient's personality characteristics, and coherence, which is how the patient perceives occurrences in the world. Each of these components and its effect on one's illness perception.

Illness perception is the patient's cognitive and subjective evaluation of the severity of his or her disease and its control of his or her life. Cognitive representations of the illness are defined as beliefs originating from the patient's common sense with regard to the illness. According to this model, patients actively process information about their illness and construct their own cognitive representations of the illness. These representations join to form the illness perception that shapes their coping and thus affects the psychological impact of the illness, such as tension and mental stress (Fortune et al. 2002).

Cognitive representations of one's health condition are based on general information learned in the past about health and sickness, as well as information received from the treating physician, family members, friends, and the media (Jopson and Morris-Moss 2003).

The features of one's illness perception are organized around five core dimensions of the illness experience: a) Causality, i.e., perceptions and attributions concerning the potential causes of the illness, b) Consequences of the illness, namely beliefs related to expected outcomes of the illness, c) Recovery/control, i.e., beliefs concerning the chances of recovery or the

patient's control of it, d) Expected duration, i.e., beliefs of its nature as an acute, chronic, or cyclic illness, e) Identity of the illness, i.e., the symptoms and indications that patients attribute to their illness (Scharloo et al. 2000). Furthermore, the cognitive representations that patients create for themselves also have emotional representations that include their emotional reactions to their illness. In other words, the cognitive aspects that comprise the illness perception have a greater impact on its psychological effect than the physical and symptomatic aspects (Fortune et al. 2002; Scharloo et al. 2000).

In addition, personality characteristics too have an effect on one's illness perception. The cognitive constructs that comprise the representations of one's illness perception characterize subsequent objective problems or perceived threats and thus affect how the illness is managed, meaning that the illness perception provides a personal interpretation of the symptoms and serves as a way of dealing with the illness (Fortune et al. 2002).

The perceived identity of the illness has an effect on the patient's personal well-being and explains the different outcomes of the illness (Hagger and Orbell 2003).

Different people have different illness perceptions, even when their symptoms are identical. The perception changes regularly in response to the diagnosis and is related to one's feelings of emotional distress, recovery, disability, and even compliance with treatment, as well as to beliefs concerning the impact of the disease or illness on one's life, how long the illness will last, and its implications for the patient and family (Petrie and Weinman 2012).

In addition, health and sickness have social implications that refer, beyond the physical condition, to a wider sense of well-being that is strongly connected to one's social environment, ability to efficiently fulfill the social commitment, and attempts to maintain normative everyday social roles (Ogege 2010).

Hence, the illness perception is manifested in the patient's perceptions of his or her illness, its consequences, and how it is generalized to a variety of life areas, such as the patient's work, family, life style, and financial situation (Petrie and Weinman 2006).

The sense of coherence, meaning the overall perception of the world as comprehensible, manageable, and meaningful, is an important factor in one's illness perception associated with the patient's grasp of his illness and his medical condition. A person with a strong sense of coherence, will have the ability to cope efficiently in stressful situations and high motivation to

act, and will also believe that the challenge he faces is comprehensible (clear) and that he has the resources to deal with it (to manage the situation). Moreover, when experiencing a failure in some situation a person with a strong sense of coherence will learn from the failure and not repeat the mistake (Antonovsky 1998).

Illness coherence has been shown to constitute a dimension that might have an important role in adjusting to illness and in responding to symptoms in the long term (Buick et al. 2002). Patients who had a better understanding of their illness were found to be less inclined to report mental distress. Therefore, providing a patient with a clear picture of his or her illness may be said to be an important and meaningful factor in preventing mental distress (Adair et al. 2009).

According to the common sense model (CMS), the illness perception is formed when patients create cognitive representations of their illness from cohesive, abstract, and available information sources in order to explain their illness in a logical way that enables them to manage it (Hagger and Orbell 2003). In this model, illness perception is related to two components: the conceptual component (attributed to the illness) and the perceptual component (experience of the symptoms). For example: My heart is beating because I am having an anxiety attack (symptoms). I feel my heart beating because I am having a heart attack (attributed to the illness).

Cognitive representations of common illnesses have been organized around five major components designated the illness perception, and these include:

Identity – the name of the illness and the symptoms associated with it.

Timeline – how long the illness will last.

Cause – what caused the illness.

Control – to what degree the illness is controllable.

Consequence – the impact the illness has on one's life (Broadbent 2010).

The information is gleaned from three sources: first, from a previous social and cultural environment; second, from external social sources, such as relatives or a doctor; and third, from the current experience with the illness based on present perceptions and prior experience with the illness. According to this model, there is a representations of the illness perception are interrelated with its outcomes (Hagger and Orbell 2003). These findings show that the more negative one's illness perception the more it is associated with deterioration of one's functional condition in the long term, indicating a that the illness representations and the illness outcomes are interrelated, as proposed by the CSM model (Bijsterbosch et al. 2010).

### **3. Frequent attenders**

This chapter will present a unique group among patients in primary care, who come to the clinic frequently and overburden the health services, the general practitioner, and the nurses.

Who are those patients who are frequent attenders: patients who pay frequent visits to medical clinics, usually unjustified by a new symptom or aggravation of a previous problem, are called frequent attenders. This uncomplimentary phrase is associated with a sense of helplessness, misunderstanding, and even distress displayed by such patients (Reis 2009). The literature is not unanimous in its definition of frequent attenders, and these are defined along a wide range as patients whose annual visits to the general practitioner exceed those of regular attenders by 3-25%. The most common definition is that which refers to 10% more doctor visits than among regular attenders. The time range examined in the literature varies as well, and ranges from 2-48 months. Studies usually focus on a period of 12 months (Smits, Brouwer, ter Riet, and van Weert 2009). There is a great degree of heterogeneity among frequent attenders. They are characterized by high chronic morbidity, psychological-mental disorders, social deprivation, deficient health beliefs, more need for information and/or for appeasement, and a poorer quality of life than patients who are not frequent attenders. Hypochondria too is associated with frequent attendance of clinics, and hypochondriacs present with physical complaints 20-45% more often than regular patients (Hirsikangas, Kanste, Korpelainen and Kyngäs 2016).

According to Rennemark, Holst, Fagerstrom and Halling (2009), illness is the main reason for frequent visits to the primary clinic. Frequent attenders often have chronic diseases that affect their daily life.

### **4. The BASIC-Ph model**

This chapter will present one models of intervention and improvement of mental resilience, as a therapeutic possibility of improving the patient's personal skills, in an attempt to improve the illness perception of patients who are frequent attenders.

There are many models for interventions and for increasing the mental resilience and self-efficacy of patients. The BASIC-Ph model, developed in 1981 by Prof. Mooli Lahad, is a multidimensional model created as a consequence of the recognition that the human psych is comprised of different aspects and these cannot be presented from a one-dimensional perspective. The premise of this model is that every person has the potential

to cope. The BASIC-Ph coping and resiliency model, developed by Prof. Mooli Lahad and Dr. Ofra Ayalon, describes coping as a continuous effort to manage life's challenges. Underlying the model is the suggestion that every person has internal forces and coping resources that may be recruited in stressful situations. The effort to survive comes from a healthy and not pathological instinct. Categorization of these coping resources produced the model's name: Belief, Affect, Social, Imagination, Cognition, Physical.

This model has seven channels in which one communicates, experiences, and responds to oneself and to the environment. These channels are comprised of body, mind, affect, family, set of beliefs, society, and imagination. They constitute an efficient coping procedure. In times of crisis every person responds differently and tries to cope in a way that is natural to him, as he perceives the world and responds to it. It is possible to identify the coping patterns that one uses in times of crisis and to practice them and even expand the existing repertoire. This process develops constantly and combines biological elements (heredity), environment, and learning. Illness is actually a situation in which one's health balance is gradually eroded and over time a state of crisis is sometimes formed. This model facilitates efficient coping in such times of crisis (Shadmi 2003).

## **5. Problem statement**

The phenomenon of frequent attenders places a burden on community healthcare services: physicians, nurses, clinical specialists, and secretaries. Frequent attenders form a significant volume of up to 50% of the clinic's activity, although constituting only 10% of the clinic's patients. Better understanding of the illness perception of this population can help clarify the motivations that bring these patients to the clinic so frequently and even find the most appropriate intervention for them, aimed at reducing the number of visits and achieving a higher sense of well-being among these patients.

In order to illustrate this issue, the current paper will deal with the perception of disease, illness, and ill health, and its meaning for frequent attenders.

## **6. Purpose of the study**

The purpose of this study is to characterize the perceptions of disease and illness among frequent attenders, and to understand the meaning of sense of health among frequent attenders.

## 7. The population

Ten patients located through information received from the database of the health services district and defined by the researcher as frequent attenders. The patient features are: patients who attend the primary clinic more than 12 times a year to see a doctor or nurse.

## 8. The method

The research method is a qualitative research method. One of the main premises of the qualitative paradigm is that when studying people there is no “objective” reality and it is not possible to indicate a simple cause and result relationship. The purpose of the qualitative study is to remain as close as possible to a unique understanding of that experienced. The study was designed with close attention to the information received from the participants (Shkedi 2015).

*Table 1. Characteristics of the study population*

Interviewees	N	Age range	Average no. of monthly visits to the general practitioner	Common diseases	Comorbidities
Men	5	23-70	6.6	Cardiac diseases such as: heart attack, bypass surgery, hypertension, type II diabetes	Digestive problems such as peptic ulcers, gastritis, and respiratory problems such as asthma, prostate problems, and Parkinson's disease
Women	5	36-70	9.4	Hypertension, asthma, cardiac diseases such as: atrial fibrillation, heart failure, hypo- or hyperthyroidism, diabetes, anxiety	Epilepsy, lipid disorder, fibromyalgia, hirsutism

The study was based on ten personal in-depth interviews with male and female frequent attenders, using a semi-structured questionnaire.

An interview guide was constructed for the study, including the following questions:

1. Define disease as you see it.
2. How does the disease affect your daily functioning?



3. Describe your health condition.
4. Tell me about your feelings following your health condition.
5. Do you feel sick? What hurts you?
6. What do you know about your health condition?

### ***Data collection procedure:***

1. Interviews with frequent attenders: The frequent attenders were summoned for an interview at random, after receiving their consent to participate in the study, from a list of frequent attenders received from the data extraction committee.
2. Data on sociodemographics, health condition, and number of annual visits to the clinic, were gathered from the database after receiving the approval of the district management.

## **9. Findings**

### ***9.1. Cognitive representations of the disease***

Among all the interviewees terms concerning implications of the disease for daily life and associated symptoms appeared in all the interviews. The interviewees spoke of feelings and sensations identified with the disease and with the illness experience. “I have varices in my colon (Diverticulitis). The food I can eat is very limited, its not a normal life.” “When I get short of breath I can become stressed.” “I have no energy, I force myself to stand up and do things.” “I feel like a rag standing on the floor.” “Its very sad to have such anger.” “Ever since the problem with my feet I haven’t been functioning normally.”

### ***9.2. Subjective experience of loss of health***

The analysis indicates that most patients feel that their loss of health has implications for personal health-related feelings and for the ability to function at home and elsewhere, at work, and is sometimes even detrimental to family relationships. It also affects the patients' mood and optimism.

“I come because I'm pained, I can't breathe.” “But I suffer pains, I have a problem.” “My son calls me sometimes. I'm sick. I tell them: I have a test. He gets annoyed,” “I'm a complex patient.” “I know there's no cure.” “I have to be careful with everything, its not like a regular patient. I have a heart aneurysm.” “I don't want to sit at home and rest. By nature I like to clean, cook, it gives me pleasure. I have no choice because of the disease. I'm restricted.” “Today I'm less optimistic because I've seen many things. I thought that maybe I'd make progress but no, my health is restricted.” “Apnea keeps me from sleeping well. It no longer works well.”

### **9.3. Sense of coherence and coping with the disease**

Patients with a high sense of coherence strongly expressed a sense of confidence in their self-ability to manage the disease, accept it, as well as feelings of high ability to cope with the state of illness. "Go to the doctor until I have more details." "Always draw strength from myself." "I have character, you know, strength of character." "The disease doesn't have the last say, I do." "You perceive yourself as a sick person: No way, if I would perceive myself as a sick person I would give everything up and I would be obedient too."

In contrast, patients with a low sense of coherence showed a lower capacity to cope with the disease and a difficulty managing the disease, as well as a sense of mental distress. "With regard to my health I'm in a bad way." "I'm unfortunate, unfortunate, my family does not understand me, the doctors don't understand me. I have no one to turn to." "I've lost all tolerance." "I feel that no one can detect my problem. I'm going crazy." "If the doctor doesn't know how I can I know? You tell me."

### **9.4. Ability to fill one's social commitment**

An explicit manifestation of the impairment and of the difficulty to fulfill the social aspect was evident among all patients in their personal functioning and in their ability to be independent, "You can't think of anything aside from your back pain." "Fatigue that I feel throughout the day. I can't work at a regular workplace." Harm to the family and to the patient's social role within the family are also evident. "My husband suffers. I come a lot to the clinic and he's old and remains alone and there is no one to care for him." "I feel that the children suffer. Why? Sometimes they want my help and I'm not at home, I'm at the clinic." Although the patients did their best to avoid any harm to the workplace, for concern of losing their job, it was still possible to find disruption of their functioning in this sphere as well. "Sometimes the disease is very disruptive. At work I constantly think about my bed, where I can lie down." "I can't work everywhere, at any place. I can't sleep at night and it is bad for my work." "My boss fired me because of the injury to my leg."

## **10. Conclusions**

The way in which the symptoms are perceived, evaluated, and interpreted by the patient necessarily affects perceptions of the disease and illness. The research findings indicate that one's cognitive interpretation of the

symptoms is a significant part of coping with the disease and of the patient's self-image as a sick person or a person with ill health. This perception often leads to disruption of normal social functioning and of the sick person's behavior in the family and at work. Cancer affects all the patient's life domains and causes feelings of depression, sexual incapacity, and even post-traumatic responses that may continue for many years after recovery (Pinquart & Forhich 2009). In the current study, one of the conspicuous effects on patients' behavior in a state of illness was their sense of coherence. It was clear that frequent attenders with a high level of coherence were better able to cope with their ill health. In addition, the patient's attitude to his or her state of health and the response ascribed to this state of health by the social environment also affected the patient's perception of the disease and of the state of health. Pinquart and Forhich (2009) found differences in coping among older and younger people, where older people showed better coping, which may be related to one's personal resources that become stronger over time and lead to personal resilience. Mental resilience, i.e., the patient's internal forces, life experience, family support, optimism, and ability to regulate feelings, which are one of the key components when coping with illness, disease, and ill health, is extremely significant as it enables the patient to efficiently cope with his or her health condition. A good illustration of this is evident in the words of Salvador Dali: "I don't do drugs. I am the drug." The interviews show that frequent attenders with a sense of optimism and confidence in their personal ability and even a certain degree of self-efficacy and understanding that they have the necessary powers in order to cope with their health condition, cope better than those who do not show these attributes.

In the case of frequent attenders, many of whom conspicuously displayed a low sense of coherence and high health anxiety, use of a mental resiliency model can serve as one of the tools for managing the problem embodied by frequent attenders (Bergh et al. 2006).

There are many models for developing personal abilities and coping with stress situations that enable development of mental resilience and self-efficacy. First and foremost, it is necessary to work with the physicians and nurses who care for these patients and to instill in them an understanding based on Engel's (1979) biopsychosocial model, which claims that medical factors alone cannot sufficiently explain the process of recovery and coping with illness, rather only a perspective that combines medical data, attending to emotional responses, and consideration for family and community factors, can enable better understanding of the patient.

With regard to the patients, one of the tools that can be used in an attempt to develop mental resilience and enhance self-efficacy and illness perception, enabling good coping with ill health, is the multidimensional model for coping with situations of stress and uncertainty (BASIC-Ph), as disease and illness are a type of crisis situation. This model relates to the individual's beliefs and values, to emotions, to the role of society, and to the body's physiological activity (Shadmi, 2003). Use of the model's components will provide patients with tools for coping with the stressful situation formed as a result of ill health as well as with better coping abilities, and in the case of frequent attenders it may also help reduce the number of visits to the clinic.

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