BELIEFS ON COPING WITH ILLNESS: A CONSUMER'S PERSPECTIVE

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Abstract—This article discusses the results of a study on beliefs on coping with illness and coping with the health care system. Using the concept mapping method, members of patient organizations ($n = 172$) sorted their beliefs on coping with illness and coping with the health care system into two dimensions (priority and content). Statistical analysis reveals eight beliefs on coping with illness, with "autonomy" and "acceptance of illness" as the most important. It also reveals eight beliefs on coping with the health care system, of which the most important is a professional relationship with the physician based on mutual trust and respect between two equal partners. It is argued that these beliefs represent idealized images of coping with illness and coping with the health care system. In relation to the political debate on responsible use of the health care system in Western countries, these findings show many patients are willing to act as responsible consumers of health care, that is, if providers of health care create an environment in which patients receive guidance in determining alternatives. Copyright © 1997 Elsevier Science Ltd

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Living with a chronic disease weighs heavily on emotional equilibrium. It makes great demands on the capacity to adapt: preserving a reasonable emotional balance, sustaining relationships with family and friends, dealing with pain and other symptoms, and developing and maintaining adequate relationships with health care professionals all take their toll [1]. Chronic disorders with an unpredictable prognosis especially, such as rheumatoid arthritis or multiple sclerosis, can test adaptive capacities to the full: work, relationships, and future plans have to be seen from a totally different perspective. Case histories aptly show how patients are torn between hope and despair, and between resistance and acceptance [2]. They also show the difficulties patients experience in finding the right attitude towards physicians and other professional caregivers: how much trust should be placed in professional care; how does one find the right balance between the tendency to grasp at every possibility of solace and maintaining the distance needed to preserve a sense of autonomy [3, 4]? Obviously, people who suffer from chronic disease are confronted with many stressful situations. According to Morse and Johnson [5], adaptation to chronic disease is largely dependent on the evaluation of these difficulties and the coping behaviour following from this evaluation. Viewed from the well-known distinction between emotion-focused coping and problem-focused coping [6], many chronic patients feel

that they have no other possibility than to cope with their disease in an emotion-focused way [7], [8]. However, the nature of the disease, the amount of available social support and a large sense of self-efficacy are factors that may be helpful in encouraging problem-focused coping, which generally speaking is more effective [9]. From this point of view it is interesting to study beliefs that chronic patients share on ideal ways of coping with different stressors and the obstacles they feel are interfering with practising these coping strategies.

Apart from the stressful situations their disease brings about, in recent years the situation of chronic patients has become even more complicated, as illness and the ensuing need for medical care are increasingly considered a social problem that figures high on the political agenda. Physicians and, in their turn, patients and patient organizations are encouraged to act like responsible users of the health care system. In The Netherlands, almost all patient organizations are a part of the Dutch Federation of Patients and Consumers (DFPC), a national platform that promotes the common interests of all its member organizations and supports the initiatives of regional patient organizations. The DFPC's contribution to the national debate on responsible use of the health care system is not so much focused on which types of medical care patients consider preferable—possibly leading to a situation in which some patients are able to claim

more rights than others. Rather, the emphasis lies on a subject that hardly rates any attention in the political debate: what do patients actually expect from the health care system, and what role does the health care system play in patients' attempts to cope with their illness and its physical, psychological and social consequences?

Thus, the DFPC is not so much interested in the actual choices its members support or reject, but in the beliefs that generate these choices. What do patients actually want from physicians, and what role do they want to play themselves? More insight into the beliefs held by patients on the health care system, physicians, and themselves as consumers of health care can contribute to better founded opinions on which choices are realistic and accepta-ble. This means we have to take a step backwards to arrive at a more considered and better under-pinned contribution to the debate on choices in medical care. In this article, this last point will only be touched on briefly. Instead, our aim is to provide an overview of the shared beliefs of patients on cop-ing with disease and the health care system. In order to acquire more insight into these beliefs, the DFPC conducted a study that allowed and encour-aged discussion among members of patient organiz-ations. This article reports the results of this study. First, we elaborate on the study's method. Second, we will present findings on the beliefs patients hold on coping with illness and dealing with the health care system, respectively. In the discussion, we expand on the possible implications of these find-ings for the debate on a responsible use of medical care.

METHOD: CONCEPT MAPPING

Beliefs on coping with illness and coping with the health care system is an awkward conversational subject because these values are difficult to express. As a result, a discussion on these topics may be overdominated by social processes—some people will have the floor too often, while others dare not to speak up, or are tempted to express extreme points of view. The method of *concept mapping*, developed by the American sociologist Trochim [10] may be helpful in better organizing the discussion. Concept mapping provides a procedure which helps the people involved to express their views. It is essential for the persons involved to first use free as-sociation on the topic under discussion, and then subsequently sort their individual associations into "content" and "priority" dimensions. Using a com-puter program, the individual arrangements are then calculated into a group map in which the rela-tive importance and the relationships of the associ-ations (by means of a Chi-square dissimilarity coefficient matrix) are presented. The calculation is a combination of multidimensional scaling, which represents the statements of two dimensions, and a

Ward's cluster analysis. More specifically, results are depicted graphically in the form of a *concept map*: shared associations are represented as clusters. Only when associations have been structured in this manner does the actual discussion through collective interpretation begin.

Concept mapping is a particularly suitable method for monitoring a discussion on a difficult subject involving a large number of people over a relatively short period of time. Making use of con-cept mapping increases the chance of bringing to light those aspects which really matter to the people involved. The sorting part of concept mapping is comparable to the better known Q-sort method, which has been used to identify patterns in ideas on health and illness [11].

In order to create optimal conditions for a discus-sion about beliefs on coping with illness and coping with the health care system, the DFPC organized a number of meetings according to the principles of concept mapping [12]. All executive members of the affiliated organizations were invited to participate. These meetings had a dual objective: to inform the DFPC about members' ideas on responsible use of medical care, and to stimulate further discussion on these topics within the various regional patient plat-forms. The invitation was accepted by 172 executive members of patient organizations. Although we have no information on motives for participation, we suspect particularly active members reacted posi-tively. In this sense, the results of the study may not be representative for the opinions of all patients.

The DFPC called two meetings in six districts. At the first meeting, the participants were asked to make a maximum of five statements on two sub-jects—"coping with illness" and "coping with the health care system". This resulted in a set of more than 200 statements. After eliminating identical and cryptically formulated statements, a set of 60 state-ments about "coping with illness" and a set of 50 statements about "coping with the health care sys-tem" remained. At the second meeting, the partici-pants arranged these statements. In three districts (85 participants) the set of statements concerned "coping with illness", while the other three districts (87 participants) were concerned with the "coping with the health care system" set. Following the con-cept mapping procedure, each participant sorted the statements individually in order of priority and con-tent. Sorting in order of priority means they had to sort all statements into five groups of equal size, each with a certain priority (from 1 = not import-ant at all to 5 = very important). Sorting in order of content means they had to compile those state-ments that had something in common (into a mini-mum of three and a maximum of 12 categories). Subsequently, these individual arrangements were calculated into a concept map. Both the concept map on "coping with illness" and that on "coping with the health care system" were discussed in
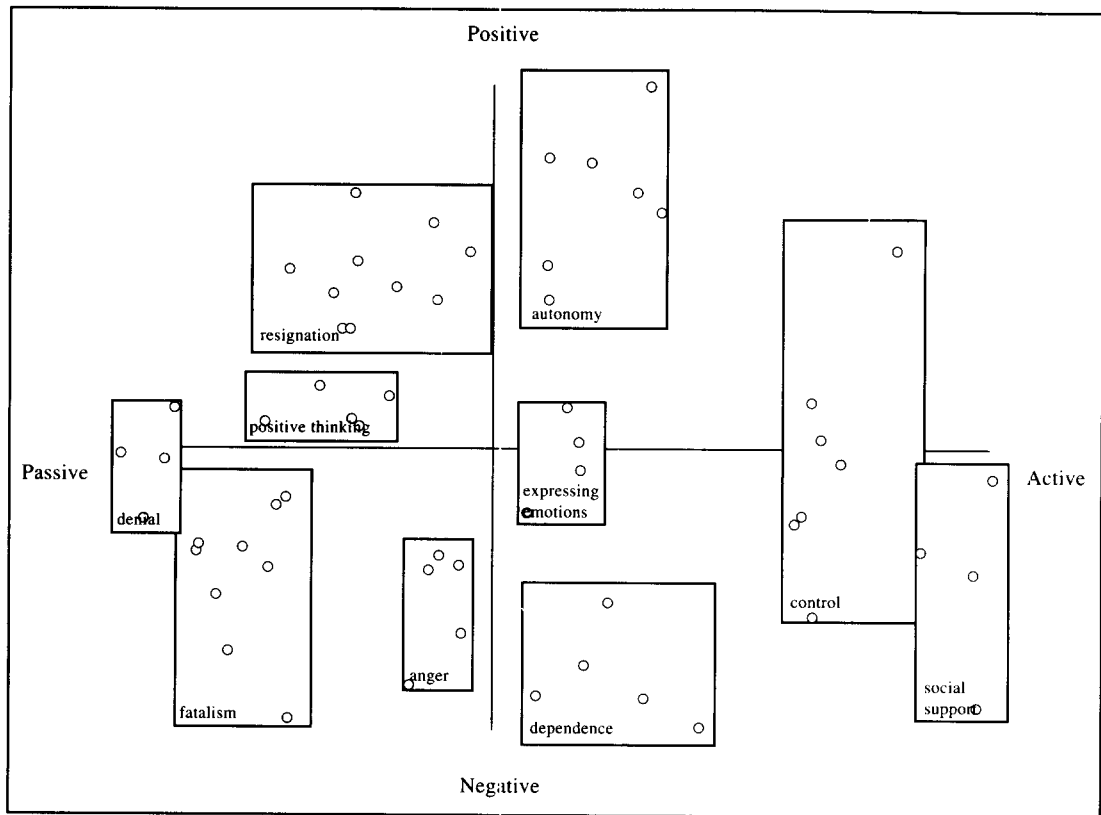
Fig. 1. Concept map: coping with illness.

groups of about 30 participants. Since there were no significant differences on the arrangement and the interpretation of associations, we will not report on the different regional meetings. Instead, we aggregated results into a new analysis that is described in the following paragraphs.

RESULTS

Beliefs on coping with illness

Most people who feel healthy can hardly imagine the adaptive tasks that inevitably accompany a chronic disorder, such as dependency on others, or living with pain and fear. What do people suffering from chronic disorders believe are important ways of coping that may be helpful in adapting to their condition? The sorting of 60 statements about beliefs on coping with illness by 85 members of patient organizations revealed 10 clusters: autonomy, positive thinking, fatalism, resignation, dependence, social support, anger, expressing emotions, control, and denial (see Fig. 1). Each of these clusters is a group representation of the individual clusterings of expressions. For example, the cluster *autonomy* contains items such as "try to maintain

autonomy" and "I myself would like to decide how I spend my days", while the cluster *social support* is a representation of items like "I will try to mobilize support from friends and family" and "talking to fellow sufferers is important to me", and the cluster *fatalism* represents items like "you have only yourself to blame when you are ill" and "disease just happens to you".*

These clusters represent idealized images of coping with illness and may be interpreted as a two-dimensional pattern. It has already been suggested that the distance between statements is a representation of their correlations—if statements are close to one another, they are more likely to form a cluster than if they are far apart. The same reasoning applies to the distance between clusters: if they are contrary to each other, they form each other's opposite, and if they are close together, they are related. In other words, the concept map reveals two dimensions. One dimension represents *positive versus negative* meaning, which strongly resembles the distinction proposed by Lipowski [13] between illness as a challenge and illness as an enemy. Patients who consider illness a challenge think of it as a new situation in their life that requires searching for new solutions. These people collect information, ask for advice when they need it, and look for alternative activities. On the other hand, illness can also be perceived as an enemy. The other dimension in which

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*A complete matrix set of the relationships between the items on which the graph in Fig. 1 is based is available from the corresponding author.

the 10 clusters can be represented is a *control* dimension. Some associations refer to the belief that one is capable of taking independent active steps to make illness bearable, while others are an expression of the belief that nothing can be done about it. In other words, either one tries to fight illness, which leads to feelings of hostility or denial, or one resigns oneself, which may result in extreme passivity and dependence.

Theoretically, a combination of both dimensions would lead to four typical ways of coping with illness. However, results show that only three out of four are represented in the ideas of the participants: a *balanced* attitude, which allows patients to regard illness in a positive way, expressed in ways of coping such as autonomy and acceptance; a *militant* attitude, which reveals a preference for considering illness as an enemy that has to be fought with force, expressed in ways of coping such as mobilizing social support and control; and a *fatalistic* attitude, in which illness is considered as an unbeatable enemy, expressed in ways of coping such as denial and dependence. Put differently, believing illness is a challenge involves a balanced attitude which allows for active as well as passive coping strategies.

From the priorities given we can infer the most preferred ways of coping with illness (see Table 1). Our findings show autonomy and resignation come first (on a scale of 1–5 these beliefs score 3.6). Preserving autonomy, protecting oneself against well-meant interference from others, and accepting the fact one is ill are values that are considered extremely important: according to the participants, these values represent ideal ways of coping with illness. Beliefs associated with a militant attitude rank second (3.0). According to the participants, this attitude has a number of advantages, as well as some limitations: not being able to face the fact that one is handicapped generates useless rear-guard actions. The participants' view of a fatalistic attitude is quite negative (with a score of 2.4).

It is important to note that all participants subscribed to this ranking order of beliefs on coping with illness, regardless of their disease or their actual involvement in the patient movement. In other words, not fighting the illness at all costs, not fostering one's illness, but finding a balanced attitude is considered the most ideal way of coping with illness. These findings gain in significance when

we look at the findings on beliefs on coping with the health care system.

Beliefs on coping with the health care system

Being ill inevitably leads to being a consumer of medical care, i.e. one consults physicians regularly and undergoes treatments aimed at curing the illness or making it more bearable. Once in this situation, the patient is expected to be capable of assuming different positions: he/she should be an active, involved patient who can discuss treatment options with his/her doctor, but should also comply with the treatments or regimes physicians find necessary. This phenomenon has been adequately described as the *double bind* imposed by the health care system on its patients [14]. Although patients are expected to fulfil their active role, because they are now better informed, more assertive, and no longer put endless trust in medical treatment, it is also clear only very few patients can afford, both psychologically and physically, to ignore their doctor's recommendations. So, it is interesting to find out what members of patient organizations think of the health care system: what expectations do they have of physicians and of themselves as patients?

The way the 87 participants who looked at this subject arranged their common associations revealed 10 beliefs on coping with the health care system: professional consultation, communication, seek advice, trust, demand, self-assertion, discussion, seek alternatives, seek support, and powerlessness (see Fig. 2). Again, these clusters represent the aggregated individual groupings of the items. For example, the cluster *professional consultation* represents items like "doctors should pay respect to their patient's wishes", "a good relationship with your doctor is built on mutual trust" and "patients and doctors should decide together on treatment plans". An expression like "I always follow doctor's advice", on the other hand, is typical of the *commitment* cluster, while expressions such as "a patient should have a say in treatment" and "I want the best care possible" are typical of the *demand* clusters. Typical items of the *powerlessness* cluster are expressions like "I fear to be an anonymous person when I am in hospital", "it is hard to be totally dependent on doctors" and "when I am with my doctor, I feel like a nobody" (see footnote).

As with beliefs on coping with illness, we can classify 10 ways of coping with the health care system in two dimensions. One (horizontal) dimension refers to the way patients think about *health care*: health care as a system on which one has no grip (left), or health care as a number of individuals providing care (right). The second dimension refers to the *position of the user* of the health care system. The clusters in the upper part describe the user as a "classic" patient who reasons along the lines of "doctor knows best" and is resigned to his/her recommendations, regardless of patient satisfaction

Table 1. Priorities in beliefs on coping with illness (*n* = 85)

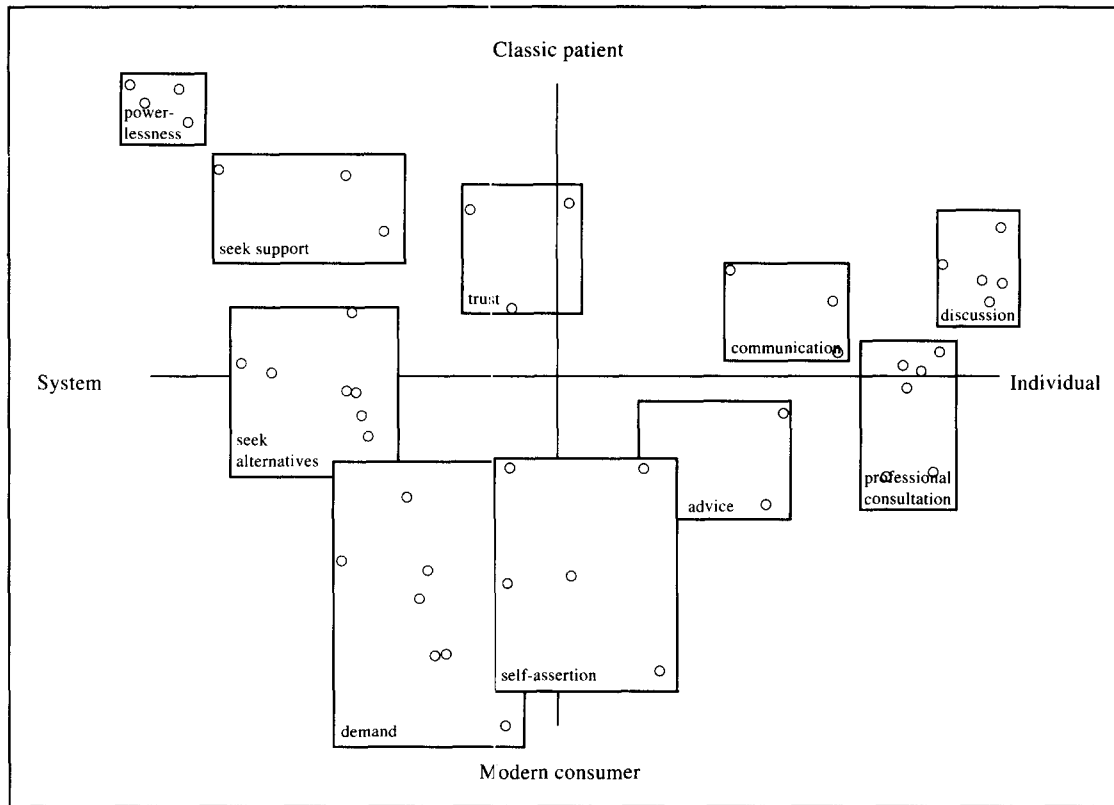|	
Autonomy	3.7
Resignation	3.5
Social support	3.2
Control	3.1
Expressing emotions	3.0
Positive thinking	2.7
Dependence	2.5
Denial	2.5
Anger	2.4
Fatalism	2.2

Fig. 2. Concept map: coping with the health care system.

with those recommendations. This passive attitude varies from the positive experience of the physician–patient relationship to the negative experience of being swallowed up by the health care system. The clusters in the lower part describe the user as a "modern" consumer with rights and duties of his own and who is capable of entering into a professional relationship with the physician in order to make sure he gets what he wants.

Again, theoretically, four variations are possible on these two independent dimensions. However, the way participants sorted the statements about coping with the health care system shows an interesting pattern of three typical strategies. The first is a position in which the health care system is perceived as being represented by individual physicians, the second is a position in which the system is viewed as a system and the user as a consumer, and the third is a position in which the health care system is also seen as a system, but the user is viewed as a patient. From this pattern of idealized images of coping with the health care system, it is obvious that participants can better integrate the consumer aspect and the patient aspect of being ill when they think of the health care system as represented by people. With respect to the latter relationship, they seem tempted into assuming an extreme position, either as a demanding consumer or as a passive and dependent patient who feels powerless. Our findings appear to suggest criticism of the health care system

is aimed at the system, and patients can deal much better with its individual representatives.

According to the participants, the preferred way of coping with the health care system is a professional relationship with the physician based on mutual trust and respect between two equal partners (on a scale of 1–5, this cluster scores 4.0; see Table 2). Coming in last, and thus representing the least ideal attitude, are associations that refer to a relationship in which the patient is a powerless, anonymous and insignificant person in the huge medical care system (score 2.1). In between these extreme positions is the belief whereby the patient has adopted a demanding, critical consumer position and regards the health care system as a supermarket where he is free to acquire the "products" he wishes to have (score 3.2). It should be noted that the latter view exists in different degrees: it

Table 2. Priorities in belief on coping with the health care system ($n = 87$)

Professional consultation	4.0
Engagement	3.9
Seek advice	3.8
Trust	3.3
Demand	3.2
Self-assertion	3.2
Commitment	3.0
Seek alternatives	2.3
Seek support	2.2
Powerlessness	1.9

comprises both very self-confident and less self-confident patients who seem to have decided they will not be caught off guard by the system. These patients try to prevent unnecessary medical procedures, but they also claim the best possible care when they think it necessary. Their idealized image is that they determine what health care should offer them.

It is interesting that of all possible beliefs on coping with the health care system, the one in which medical care is represented by individuals is considered the most important. A professional relationship in which physicians try to resolve the problem in cooperation and consultation with the patient is widely preferred. The physician who wishes to live up to this idealized image must be both professional and empathic.

DISCUSSION

The results of this study show that beliefs on coping with illness represent 10 categories, varying from autonomy and resignation to anger and fatalism. In addition, the graph of these 10 categories can be interpreted on two dimensions, being a control dimension and a positive versus negative dimension. Beliefs on coping with the health care system can also be categorized in 10 categories, varying from professional consultation and engagement to seek support and powerlessness. These categories can also be interpreted in a two-dimensional way: the dimension of health care as a system versus health care as number of individual doctors and nurses and the dimension which refers to the position of the user. Apart from the interesting patterns these categories reveal on beliefs on coping with illness and on coping with the health care system, the priorities given to the different categories also show interesting results. When we concern the categories with the highest priority as the most ideal ways of coping with either disease or the health care system, the results can be interpreted in the following way. Comparing both the idealized images of coping with illness and those of coping with the health care system reveals a remarkable similarity. The ways of coping with illness that are considered the most preferable refer to accepting illness and maintaining autonomy. The most preferred ways of coping with the health care system, on the other hand, refer to an equal relationship between the physician and the patient. So, patients seem to be willing to accept their illness and they also seem willing to acknowledge dependence on physicians, on the condition they do not lose autonomy and self-respect.

Since many research findings suggest the opposite, this is a remarkable result. For example, many studies show that many patients suffering from chronic disease actually use passive and avoidant coping strategies—their condition, so to speak, seems to force them to focus their coping efforts on control-

ling emotions which result from their disorder [7], [8]. However, active coping strategies which are problem-focused or are aimed at facing emotions in an approach-like manner appear to be more effective ways of coping. In this respect it is interesting to notice that the few studies that make a distinction between type of disease and the typical difficulties following from it find that chronic patients, depending on their disease, also use problem-focused coping strategies and strategies that can be categorized as approach-like coping with the emotions resulting from their condition (e.g. positive reappraisal and "intentional denial"). A number of studies show that especially life-threatening diseases, such as cancer and heart diseases, call for more problem-oriented coping (such as search for information) than do other diseases such as diabetes or rheumatic conditions, which dot not seem to cause the same amount of alarm [15–18]. On the other hand, diseases with an unpredictable course, such as multiple sclerosis, show a dominant emotion-avoidant strategy, targeted on suppressing the panic that accompanies the destructive insecurity regarding the future course of events [19]. In sum, our findings show that although patients may not always be able to cope with disease in the way they prefer, their beliefs on ideal ways of coping undoubtedly reveal a preference for active, approach-like ways of coping with their condition.

In contrast, research on coping with the health care system is lacking. Yet, both physicians and lay people feel patients are asking too much of medical care [4]. Whatever the truth, it must be stressed that patients should not really be blamed for their (excessive) demands, as they are encouraged to make them by the health care system itself. Patients are depicted as incapable of adopting a mature, balanced attitude towards their illness. Depending on the gravity of the disease, the patient's personal and social background, and his/her experiences with the health care system, many feel patients fall back too easily on behaviour that leads to an excessive use of medical care—either through demonstrating demanding behaviour, or by slavishly following the physician's recommendations. However, the results of our study point in another direction. There is a difference between the attitude towards physicians that is considered ideal and the way many patients actually behave—regardless of whether this is due to one's own limitations, or to the functioning of the health care system. Put differently, our results point to the fact that an analysis of the discrepancies between the ideal and the actual ways of coping with the health care system is required. Following this line of reasoning, future studies should also take into consideration the extent to which there is a difference between beliefs focusing on the relations with physicians and those focusing on the relations with supporting personnel. Such an analysis may be helpful in finding out whether the relations with

nurses and other supporting personnel do not need to be idealized and, in that sense, are more "real". That is, since supporting personnel may be more able to communicate with patients in an equal way, they may also be more able to respond to patients' needs in a more sensitive manner. In that respect, patients' contacts with supporting personnel may be of more assistance in guiding them through the complexities of the health care system. However, more research is needed to answer the questions related to this issue.

Despite the interesting results of this study, some critical comments have to be made concerning the method of concept mapping. Although concept mapping appears to be an adequate means of eliciting relevant associations from the persons involved, the method has not been widely used in a research setting. Of course, potential problems concerning applying concept mapping as a research method do not necessarily concern the procedure of brainstorming on expressions relevant to the topic of the study [10]. Neither are there to be any problems concerning the sorting procedures as they resemble very much the better-known Q-sort method. Potential problems, then, may arise when one wants to compare the results of concept mapping with more current research methods. Bearing this in mind, the results of this study have to be interpreted with caution until some form of corroboration is available from other studies. Still, we feel that our exploration of beliefs on coping with illness and coping with the health care system has produced some interesting results on a topic on which not much is known yet. We hope, therefore, that this study may be a starting point to explore this topic more elaborately.

All in all, our findings suggest widely held opinions on over-use of medical care by patients should be re-evaluated and adjusted. A large number of the patients participating in our study have no wish to be demanding users of health care who will only be satisfied with the latest medical gadgets. Based on the results representing the patient's perspective on choices in medical care, one would rather wonder how conditions can be created which will better enable patients to decide about the care they need and how they can make such a choice in proper consultation with physicians. According to the DFPC, one of the most important conditions is that physicians take time to guide patients in determining alternatives and weighing pros and cons [12]. Many patients would be only too glad to have a constructive discussion with physicians so that they are able to make an educated choice in dealing with medical care in a responsible manner—and thus to contribute to a well-considered use of facilities. But the health care system must position itself in a way that makes this possible.

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