

Review

Patient empowerment in theory and practice: Polysemy or cacophony?

Isabelle Aujoulat^{a,*}, William d’Hoore^b, Alain Deccache^a

^aHealth and Patient Education Unit RESO, Université Catholique de Louvain, Bruxelles, Belgium

^bHospital Administration Unit HOSP, Université Catholique de Louvain, Bruxelles, Belgium

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Abstract

Objective: This paper examines how the term “empowerment” has been used in relation to the care and education of patients with chronic conditions over the past decade.

Methods: Fifty-five articles were analysed, using a qualitative method of thematic analysis.

Results: Empowerment is more often defined according to some of its anticipated outcomes rather than to its very nature. However, because they do not respect the principle of self-determination, most anticipated outcomes and most evaluation criteria are not specific to empowerment. Concerning the process of empowerment, our analysis shows that (i) the educational objectives of an empowerment-based approach are not disease-specific, but concern the reinforcement or development of general psychosocial skills instead; (ii) empowering methods of education are necessarily patient-centred and based on experiential learning; and (iii) the provider–patient relationship needs to be continuous and self-involving on both sides.

Conclusion: Our analysis did not allow for the unfolding of a well-articulated theory on patient empowerment but revealed a number of guiding principles and values.

Practice implications: The goals and outcomes of patient empowerment should neither be predefined by the health-care professionals, nor restricted to some disease and treatment-related outcomes, but should be discussed and negotiated with every patient, according to his/her own particular situation and life priorities.

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1. Introduction

People who are told that they will have to live with a chronic disease often have to face major changes in their everyday life. Not only do they have to learn a lot about the disease and its treatment, they are also often told to integrate a number of new lifestyle or treatment-related behaviours into their everyday life. These behaviours may be difficult to adopt on a long-term basis, as they often conflict with existing behaviours, priorities or projects. Thus, the need for change occurs not only at a behavioural level, but also at a

psychosocial level. Indeed, “being chronically ill is a total experience influencing all facets of life” [1]. As patients become aware of the life changes they will have to consent to in order to adjust to their disease, they may experience a distressing feeling of powerlessness. Powerlessness was defined by Freire (1973, cited by [2]) as occurring when an individual assumes the role of an “object” acted upon by the environment, rather than a “subject” acting in and on the environment. Powerlessness has been acknowledged as a determinant of ill health [3]. Conversely, empowerment may be considered as a health enhancing process [4,5].

In the field of health-care, empowerment has been acknowledged as an alternative to compliance in order to guide the provider–patient relationship. Whereas in the more traditional compliance-oriented approach to health-care, patients are seen as the recipients of medical decisions and prescriptions, the empowerment-oriented approach views

* Corresponding author at: Health and Patient Education Unit RESO, Faculté de Médecine, Ecole de Santé Publique, Université Catholique de Louvain, 50 Avenue Mounier, B-1200 Bruxelles, Belgium.

Tel.: +32 2 764 50 70; fax: +32 2 764 50 74.

E-mail address: isabelle.aujoulat@reso.ucl.ac.be (I. Aujoulat).

patients as being responsible for their choices and the consequences of their choices. However, there are many interpretations of the term “empowerment”, based on different understandings of the concept [6].

The idea of empowerment is rooted in the “social action” ideology of the 1960s and the “self-help” perspectives of the 1970s [2]. It puts an emphasis on the rights and abilities rather than deficits and needs of the individuals and communities [7]. In the 1990s, the Ottawa Charter for Health Promotion [8] has made empowerment a key issue in the theory of health-promotion, which focuses on positive health enhancement rather than only ill-health prevention, mainly through the improvement of social conditions [9]. In the field of community psychology or human resources development, empowerment has been conceptualised as being at the crossroads of individual and community or organisational development. In this perspective, individuals contribute to a common goal within a collective process of social change [3,5,9,10]. In other words, one central feature of community or organisational empowerment is to make use of individual competence to collectively initiate changes.

In the field of health-care, an attempt to clarify the concept was done by Gibson [11]. Her analysis shows that a great number of characteristics are associated to the concept, making it difficult to think of empowerment consistently and in operational terms, in order to allow for its implementation in health-care settings. While some authors feel comfortable with the idea that empowerment may take on a different form in different people and within different contexts (e.g. [7]), other authors (e.g. [2]) have argued that in order to establish the utility of the term “empowerment” for theory as well as for practice, a precise and functional definition was needed.

This paper examines how the term “empowerment” has been used in relation to the care and education of patients with chronic conditions over the past decade. Based on the results of a literature review, we seek to establish whether it has acquired a consistent meaning and whether some guidelines on how to put it into practice may be issued.

2. Methods

Three international databases – Medline, Current Contents, and PsycInfo – were searched over a 10-year period (1995–2005), using two keywords: “patient education” and “empowerment”. The results of this search for each of the databases were 145, 59 and 18 articles, respectively. The abstracts of all articles were checked so as to select the articles according to five inclusion criteria:

- the article should concern adult patients with a somatic chronic disease (articles relating to psychiatric patients or children were excluded);
- the information contained should refer to the empowerment of patients (articles relating to the empowerment of staff were excluded);

- the aim of the patient education activities described in the article should be a therapeutic one (articles relating to palliative care were excluded);
- the patient education activities described or mentioned in the article should occur within a context of health care, and involve health-care professionals (articles relating to e-health were excluded);
- the patient education activities described or mentioned in the article should occur in industrialised countries (articles relating to developing countries were excluded).

After checking the abstracts, 62 articles were selected for the present discussion. After reading the articles, we further excluded 11 articles because they did not tackle the issue of empowerment although the word was present in the abstract. As the research was theoretical and descriptive, and not applied or comparative, no specific selection criteria were defined regarding the type of publication. We therefore initially included 23 research articles and 28 theoretical papers. At the end of the writing process, we manually checked the contents of Patient Education and Counseling for articles published or accepted for publication in 2006, and further added four research articles to our selection. Our work is therefore based on the analysis of 55 articles published between 1995 and 2006, including 27 research articles [12–38] and 28 theoretical papers [39–66].

The articles were reviewed using a qualitative method of thematic content analysis. The categories of analysis had been pre-determined according to five research objectives: (1) Definition of patient empowerment, i.e. what does it mean to empower patients? What is an empowered patient? (2) Identification and description of specific educational objectives contributing to the process of patient empowerment. (3) Identification and description of methods and strategies used to implement activities aiming at enhancing patient empowerment. (4) Identification and description of attitudes and communication styles favourable to the process of empowerment. (5) Identification and description of evaluation methods and indicators to measure the success of activities intended to empower patients.

3. Results

Our selection of articles included 27 research articles [12–38] and 28 theoretical papers [39–66]. As we generally expect a concept to be more systematically and precisely defined in research papers, the results which are presented in this section are based on the analysis of the research papers only. The theoretical papers were used in a secondary analysis to refine and discuss the results that emerged from the analysis of the research papers, and are therefore presented in the next section. Our results are presented according to the five above-mentioned pre-determined thematic categories of analysis, i.e. definition of

empowerment, educational objectives, methods, attitudes and communication styles, and evaluation.

The results presented hereafter are descriptive of what was found in the literature and do therefore not necessarily reflect the authors' view on empowerment.

3.1. Scope and methods of the selected research papers

Half of the selected research articles (15/27) were evaluation studies aimed at evaluating what effect or impact an empowerment-based intervention had had on patients [12,13,15,17,18,22,25,26,30–32,34–36,38]. The methods included randomised control trials [12,15,17,20,22,25,38], quasi-experimental studies [13,18,30,32,34,36], and a longitudinal pre-test/post-test design [31,35].

Qualitative methods were used in 6 of the remaining 12 research articles [14,16,23,27,29,33]. The articles using qualitative methods aimed to understand and describe better the experience or meaning of (dis)empowerment to patients, or the characteristics of an empowering provider–patient relationship [14,16,23,27,29,33].

Other methods and aims included:

- two statistical factor analyses to derive and evaluate the validity and reliability of two instruments aimed at assessing empowerment: Anderson et al.'s [21] Diabetes Empowerment Scale (DES), which is a measure of diabetes-related psychosocial self-efficacy, and Kettunen et al.'s [37] Empowering Speech Practices Scale, which assesses the empowerment of dyadic counselling [37];
- two correlational descriptive studies to describe the perceived psychosocial self-efficacy in a population of 90 diabetic patients attending diabetes classes [19], or to assess the information that is important to men with prostate cancer, their preferred participation in decision making, and factors influencing the information needs and participation preferences [20];
- one systematic review to test the effects of patient versus provider-behaviour based interventions on the modification of provider–patient interaction and provider consulting style [28];
- a semi-qualitative study based on content analysis interview transcripts to ascertain the views of patients and patient care teams on a recently developed diabetes passport, meant to contribute to the empowerment of patients [24].

3.2. Definition: a personal or transactional process, and many different anticipated outcomes

Our analysis did not allow for the unfolding of a well-articulated theory that would provide for a consistent definition of patient empowerment. The word “empowerment” is poorly defined, with authors often referring to some anticipated outcome, such as self-management or self-efficacy to explain what they mean, rather than

defining what “empowerment” according to its very nature. However, the underlying philosophy of an empowerment-based approach is recalled in many of the selected research articles [13,15,18,20,21,23,25,26,28–30,34], i.e. a philosophy which views human beings as having the right and ability to choose by and for themselves. Self-determination therefore appears to be a strong guiding principle of empowerment-based interventions.

Our analysis suggests that there are two dimensions to the process of patient empowerment: an inter-personal dimension and an intra-personal dimension. As a result, empowerment may be apprehended either from the point of view of the provider–patient interaction [16,23,24,28,33,37], or from the point of view of the patient alone [12,13,15,17–22,25–27,29–32,34–36,38], or both [14,25,33]. When it is seen from the point of view of the provider–patient interaction, empowerment is considered as a process of communication and education in which knowledge, values and power are shared. When the process of empowerment is seen from the point of view of the patient, empowerment is considered as a process of personal transformation. Whereas the first definition, i.e. empowerment as an interactive process, suggests that power is “given” by someone to somebody, the second definition, i.e. empowerment as a personal process, suggests that power is “created” within someone. Although the expected outcome is the same, i.e. to gain more power over one's life, the nature of the two processes is very different. At the crossroads, McWilliam et al. [14] view empowerment as the result of both an interactive and a personal process, where the emergence of “power” (or potential) is facilitated by a caring relationship, and not merely given by someone, nor created within someone. In other words, the emergence of a person's potential as a result of an empowerment process, may be viewed as a co-creation, within a true partnership.

The outcomes most frequently associated to the process of empowerment were found to relate to the disease and its treatment, and included self-management of disease and treatment [12,17,26,28,39,31,34], self-determination of health and treatment-related goals through participation and negotiation [13,15,16,18,20,21,23,25–28,30–35], and self-efficacy regarding disease and treatment-related behaviours [12,13,15,18,19,21,28,32]. Moreover, disease and treatment related outcomes included enhanced knowledge regarding one's disease and treatment [25,28], and some clinical outcomes such as a better glycaemic control [31] or better pain management [20,33].

Other anticipated outcomes of the process of empowerment were found to relate to the psychosocial aspects of living with a chronic disease, or to be unspecific. Psychosocial and life-related anticipated outcomes were found to include an enhanced quality of life [12,28,31,33], an enhanced capacity to cope with negative feelings [25,33], a personal transformation of self in relation with one's environment [29,34], and a better psychosocial adaptation [31,35], which was sometimes defined as the capacity to resume life activities sooner [33]. Non-specific anticipated

outcomes included decision and implementation of behaviour changes [21,25,29], enhanced control [31,33], personal satisfaction [33], and responsibility [26].

3.3. Educational objectives: acquisition or reinforcement of general psychosocial skills

The main characteristic of an empowerment-oriented educational objective is that it is not specific to a particular disease or treatment. Indeed, across our selection of research articles, an empowerment-based intervention was found to acknowledge the importance of acquiring or reinforcing psychosocial skills in patients. Psychosocial skills are not only useful for the individual's everyday life, but can also be applied to disease and treatment-related issues, as well as to provider–patient interaction-related issues. An empowerment-based approach therefore seeks to reinforce some general abilities in people, such as the ability to identify needs and psychosocial problems [12,34], determine personal goals [12,34], define strategies to achieve the self-selected goals [12,33], solve problems [12,26,33,34], manage stress and cope with emotions [12,21,34], seek and attain appropriate social support [12,21,34], get and stay motivated [12,34], seek information [34], negotiate [21,34], ask questions and express preferences [34], and communicate [21]. Through the reinforcement of such skills, as a result of the empowerment process, the patients' self-efficacy [12,15,33], assertiveness [34], self-awareness [31], and sense of autonomy [31] are expected to be maximised.

3.4. Methods: patient-centred education based on experiential learning and the facilitation of self-reflection

As only a few authors in our selection of research articles provide for a full description of their empowerment-based educational interventions, the methods and strategies used are poorly described. Our analysis suggests that the process of empowerment, whether it is implicitly or explicitly described, would occur mainly through self-reflection, and that self-reflection could be facilitated through the provision of adequate educational or self-reflective tools, or by relating to someone in a specific way.

Most of the empowerment-based educational interventions that are described in our selection of articles occur through group interventions [12,22,25,26,30,31,34,35]. A patient-centred approach based on experiential learning principles is the key feature of an empowerment-based programme, such as those described by Anderson et al. [12], Cooper et al. [26], Keers et al. [31], and Pibernik-Okanovik et al. [34]. Practically, it means that explanations related to a topic are followed by group discussions, practical exercises, and self-reflection in order to individually set goals and plan how to practice at home. In the programme described by Anderson et al. [12], the patients are invited to bring along

with them a relative or friend who participate in the group discussions.

3.5. Empowering attitudes and communication styles: a continuous and self-involving relationship

Some key-features of an empowering relationship are well described, suggesting that empowerment is more about “what you are” than “what you do”. The type and features of a provider–patient relationship that allows for an empowerment process to take place are best described by McWilliam et al. [14], Paterson [23], and Chang et al. [29], as these authors explored the meaning of empowerment or the features of an empowering relationship from the point of view of patients. According to McWilliam et al. [14], the empowerment process occurs while the patient tells his/her story and the health-care provider facilitates the understanding they both gain of the patient's situation and situatedness, thus adding or creating meaning to the patient's experience. The main features of an “empowering” relationship were found to be continuity, patient centeredness, mutual acknowledgement, and relatedness. On the other hand, discounting experiential knowledge and providing inadequate resources, particularly in terms of time and continuity, were found to be the main features of a disempowering relationship [23]. Other attitudes reported as contributing to the process of empowerment included:

- to construct a positive atmosphere, demonstrate interest and provide a positive regard and non-judgmental responsiveness [14,23,26,34,37];
- to pay attention to the patients' priorities and concerns, usually through an active listening of their life-experience, followed by a self-reflective dialogue [14,16,18,23,26,29,30,37];
- to support the patients' autonomy and actively encourage them to participate in the consultation and the health-related decisions [14,17,18,33,34,36];
- to offer individualised information and advice [37];
- to allow the patients to express their emotions, and be there as an emotional support [34];
- to be aware that the patient needs time, and allow the patient to take the necessary time to make decisions [23] or practice tasks [18];
- to facilitate the evaluation of changes in one's representation of self [14].

What fundamentally varies when empowerment is considered as a process that emerges from a particular type of educational relationship or interaction, as opposed to a process that is made possible through the “provision” of information or education, is the role of the health-care provider involved in the process of empowerment. Both McWilliam et al. [14] and Paterson [23] stressed that not the patient alone, but both the patient and the professional are changed, as a result of an empowerment process, as an

empowering relationship implies that the professionals have to unlearn being in control.

3.6. Evaluation methods and criteria: not specific to empowerment

We have described the educational objectives of an empowerment-based intervention as relating to the acquisition or development of general psychosocial skills so as to make the individual more competent to deal with disease, treatment, and life-related issues (see Section 3.3). However, the evaluation methods or criteria presented in our selection of research articles to assess the impact of an empowerment-based intervention are not in line with this general objective of skills-development, but with some of the anticipated outcomes of empowerment that were listed in Section 3.1, and include: (i) disease and treatment-related indicators, such as clinical outcomes [12,17,26,28,31,33,34], perceived control over the disease [22], health beliefs concerning the disease [22], satisfaction regarding treatment [22], and one's level of health literacy regarding one's disease and treatment [28]; (ii) provider–patient interaction-related indicators, such as the patients' satisfaction regarding consultation or intervention [13,18,25,28,32], the number of questions asked by the patient during the consultation [32], the level of self-efficacy in asking questions [32], one's level of preference regarding participation in the consultation [15]; (iii) psychosocial and life-related indicators, such as the patients' quality of life [30,31,34], the level of anxiety, depression and/or emotional distress [15,25,28], the number of days of sick-leave [25,28], the perceived physical and emotional health [25,28], changes occurring in the individual's behaviour or self [12,14].

Three (3) scales were found to be specifically developed to measure patient empowerment [12,18,37]. Whereas the scale developed by Kettunen et al. [37] is designed to measure the process of an empowering counselling encounter, Anderson et al. [12] and Pellino et al. [18] attempted to develop scales that are designed to measure the outcome of an empowering intervention. The items presented in Pellino et al.'s scale [18] relate to the patients' general satisfaction with the intervention, and are therefore not specific of empowerment. The scale developed by Anderson et al. [12] is a measure of psychosocial self-efficacy related to specific disease management behaviours.

In our selection of articles, indicators of empowerment defined by the patients themselves were described in two (2) articles only. In Anderson et al.'s article [12], the patients expressed as a result of their empowerment process that they felt they understood their disease and were able to fit it in their life in a more positive manner, and that they were comfortable asking questions to their physician. In Chang et al.'s [29] study, the patients reported that they were confident and actively involved in negotiating the goals of their care plan, that they had redefined health, revitalised their sense of self and the desire to live for themselves, and that they had gained more strength to help others.

4. Discussion and conclusion

4.1. Discussion

The key features of an empowerment-based approach are ideology driven and concern choice and responsibility on the one hand, and skills-development so as to become more competent in relating to self and others, and dealing with one's disease, life and environment on the other hand. These features clearly posit empowerment within a humanistic approach of human motivation and development, which postulates that there is an intrinsic tendency in humans toward self-growth or “self-actualisation” (e.g. Rogers [67], Maslow [68]), as well as a need for competence over one's environment, also called “effectance” [69] or “mastery motive” [70]. Moreover, the features described by the various authors as being central to the concept of empowerment are very close to the features defined in Deci & Ryan's Self-Determination Theory (SDT) [71] as contributing to intrinsic motivation, namely competence, relatedness and self-determination (or autonomy) [72]. Studies on SDT and intrinsic motivation in relation to chronic illness and adherence have shown the importance of self-determined or autonomously regulated goals on health outcomes [73–75]. However, only one article in our selection for the present review has explicitly made reference to SDT [38].

Another common feature of empowerment-based interventions in our selection of article concern the process of learning: although the methods of education were poorly described, empowering interventions were found to be necessarily patient-centred and based on the principles of experiential learning. Moreover, empowerment was said to occur within a continuous and self-involving relationship which facilitates self-reflection and the expression of emotions, preferences, fears, personal goals, etc.

However, notwithstanding the commonalities that were found to describe empowerment, the multiplicity of possible anticipated outcomes and the corresponding indicators that were found to be associated to empowerment in an attempt to operationalise the concept, were found to be a source of ambiguity rather than clarification.

Indeed, according to the principle of self-determination, more often termed “choice and responsibility for one's choices” in our selection of articles, one would expect the indicators of empowerment to be defined by the patients themselves, rather than by a professional. However, some of the anticipated outcomes of empowerment that were found in our analysis are still very medically oriented and prescriptive (i.e. clinical outcomes, predetermined areas of quality of life, etc.), and are therefore not congruent with the principles of self-determination and responsibility. This is the case of most disease and treatment-related outcomes. Although they are convenient and necessary for health-care providers to observe, they could be the result of compliance as well, i.e. a situation where patients are expected to do as they are told to do.

Self-management and shared decision-making were the most frequent anticipated outcomes to emerge from the analysis of the research papers. The analysis of the theoretical papers in our selection confirmed self-management [39,43,47,54,62] and participation in the consultation and the decision-making process [39,44,46,55,56,60–62] as important and relevant outcomes of empowerment. However, according to the principles of empowerment, self-management may be considered a relevant outcome of empowerment only if it is viewed as resulting from a process of self-determination, in which patients are allowed to determine their own goals and their own strategies to attain these goals [39,46,52]. As the process of decision-making is influenced not only by disease and treatment-related issues, but also by a variety of psychosocial aspects of living with a chronic illness, health-care providers should be aware that the patients' personal goals may differ from what they believe is best for the patient. Time and experience have been stressed as important factors for empowerment. Time is often needed to allow patients to make their own decisions, to negotiate treatment options or schedules with their health-care providers, or to consent to some medical decision that has been presented to them as being the best for them. Two studies which examined the point of view of patients on the particular aspect of participation found that some patients did not consider their participation in health-care decisions as a desirable outcome of their encounter with a health-care provider [20,27]. Instead, some patients expressed the desire to delegate the responsibility for decision-making. According to the principle of self-determination, Anderson et al. [76] argue that those patients who choose freely to hand over responsibility should still be considered empowered. In this case, they are responsible for their choice, if not for their treatment. Indeed, in an empowerment-based approach, the focus is not on defining a particular type of behaviour, but on how the behaviour is defined as a goal to be achieved by a particular individual. Empowered patients should therefore not be strictly considered a synonym of activated patients who, as a result of rejecting "the passivity of sick role behaviour and assuming responsibility for their care (...) are more knowledgeable about, satisfied with, and committed to their treatment regimens" [77].

Another concept which was found to be frequently associated to empowerment was Bandura's concept of self-efficacy [78], but it is not clear from our selection of articles whether self-efficacy should be considered as an outcome or a precursor of empowerment. Indeed, it was referred to either as the goal of an empowerment-based intervention [15,21,55], as an indicator of empowerment [12,13,18,21,28,32,33,39,40], or as a predisposing factor or a skill to be developed in order to allow for an empowerment process to take place [19,33,44,46,52,54]. However, the role of self-efficacy in self-management effectiveness, and its relation to health outcomes in patients with various chronic conditions have been well established by Lorig et al. [79]. Consequently, self-efficacy-enhancing interventions may be recommended as

patient education strategies aimed at enhancing self-management effectiveness [80–82].

To acknowledge self-efficacy as an important dimension of empowerment, implicitly defines patient empowerment as a process of behaviour change. Yet, if the idea of change or transformation is indeed central to the concept of empowerment [12,29,40,41,52,62], behaviour change alone is considered by some authors as insufficient to define empowerment. Indeed, a few authors consider that empowerment is a process of personal change, whereby one's relation to self and to one's environment is changed [29,34,39,47,62]. This is congruent with the previously reported importance of self-reflection within the process of empowerment. According to Feste [83], self-awareness and choice are the central themes in empowerment, and "People are empowered when their conscious choice making is the force in control of their decisions". Thus, the existence of an unconscious dimension involved in people's motivation and commitment to change is acknowledged, suggesting that empowerment is primarily about changing one's self, rather than primarily changing behaviours or acting on one's environment.

4.2. Conclusion

Empowerment may be defined as a complex experience of personal change. It is guided by the principle of self-determination and may be facilitated by health-care providers if they adopt a patient-centred approach of care which acknowledges the patients' experience, priorities and fears. In order to be empowering for the patient, therapeutic education activities need to be based on self-reflection, experimentation, and negotiation so as to allow for the appropriation of medical knowledge and the reinforcement of psychosocial skills. As they get empowered, patients may develop a greater sense of self-efficacy regarding various disease and treatment-related behaviours, and may express changes in life priorities and values. As a result of their empowerment process, patients are expected to better self-manage not only their illness, but their lives as well.

4.3. Practice implications

Health-care providers need to adopt a patient-centred approach if they want to effectively translate empowerment into their clinical practice. This requires from health-care providers that they get personally involved in the relationship with their patients and implies a shift in the representation of their roles, from skilled technician to person, and from knower to facilitator. An empowering educational process implies that health-care providers have to accept to acknowledge the fact that they do not know in advance what the outcome of the empowerment process for a particular individual will be: as scientific knowledge is balanced against individual priorities and values, some patients may decide that they want to leave with their physician the responsibility for some aspects of their treatment, while other

patients under similar circumstances would be happy to learn to self-manage most aspects of their illness and treatment.

A recent narrative by a physician [84] provides for a good illustration of a truly empowering relationship, in which both the physician and the patient are learning from each other and are changed as the result of the empowerment process. In his narrative, Dr. Ting explains how he was brought to relinquish medical control in a case where he decided to accompany one of his patient's decision not to follow a recommended treatment, so as to be able to lead for another few years a life that would remain meaningful to him.

To apply the principle of self-determination means to acknowledge that only the patients can identify for themselves what are the areas of their lives they feel are most threatened by their illness, and in how far different health-care options, including self-management decisions and tasks, are linked to meaningful outcomes in their lives. To apply the principle of self-determination does not mean that the patients should be left alone to decide what is best for them. It is the health-care providers' responsibility to provide for a feeling of security and a motivation to learn, by conveying the message that the management of a chronic illness is a shared responsibility in the long run, and that health-care options and responsibilities may be experimented, and need to be negotiated and decided upon, according to both psychosocial problems and preferences identified by the patient, and medical problems and possibilities identified by the health-care providers.

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