We are IntechOpen, the world’s leading publisher of Open Access books
Built by scientists, for scientists

4,300 Open access books available
116,000 International authors and editors
130M Downloads

154 Countries delivered to
TOP 1% Our authors are among the most cited scientists
12.2% Contributors from top 500 universities

WEB OF SCIENCE™
Selection of our books indexed in the Book Citation Index in Web of Science™ Core Collection (BKCI)

Interested in publishing with us?
Contact book.department@intechopen.com

Numbers displayed above are based on latest data collected.
For more information visit www.intechopen.com
Promoting Patient-Centered Care in Chronic Disease

Ana Monteiro Grilo,
Margarida Custódio dos Santos,
Ana Isabel Gomes and Joana Santos Rita

Abstract

Nowadays, many people around the world are seeing their lives being shattered and even shortened due to one or more chronic conditions. Chronic illness is a dynamic ongoing process that is determined by a complexity of factors. Patient literacy, motivation, emotional well-being, and resources play an important role on patient adaption and are important challenges for healthcare providers. A systematic patient-centered approach that enables chronic patients to play an active role in their condition management and in the decision-making process on a day-to-day basis is required. However, some studies show that health professionals do not always guide their actions by Patient-centered orientation, either by personal issues or by professional and/or institutional barriers. The present chapter aimed to provide a comprehensive approach to patient-centered care in chronic disease and offer a structured guideline as a tool for formal academic education in chronic patient-centered care. This chapter is structured in five sections: (1) Chronic disease: the challenge of the twenty-first century, (2) The patient with a chronic disease, (3) Patient-centered care in chronic diseases, (4) Issues and barriers to achieve patient-centered care, and (5) Guide tool for health professionals’ training and education in patient-centered care.

Keywords: patient care, chronic disease, patient empowerment, medical students, health professionals

1. Introduction

Patient-centered care is defined as the professional’s attitude during healthcare that is closely congruent with a responsive to patient’s wants, needs, and preferences [1]. Although patients differ in their preferences and interaction styles, the patient-centered style has been associated with higher rates of satisfaction, better adherence, and better treatment,
particularly in the management of chronic illness [2]. Effective chronic disease management involves continued and coordinated action by the patient and the physician: dynamic partnership with mutual responsibilities and accountabilities.

Nevertheless, some studies conclude that health professionals do not always guide their actions by patient-centered orientation, either by personal issues (e.g., personality characteristics, development of specific communication skills) or by professional and/or institutional barriers [3]. Training health professionals, either during the academic years or in postgraduate courses, can promote the change that is required to accomplish patient centeredness.

The present chapter aimed to provide a comprehensive approach to patient-centered care in chronic disease and offer a structured guideline as a tool for health professionals’ training and education in patient-centered care. It will be structured in five sections: (1) Chronic disease: the challenge of the twenty-first century, (2) The patient with a chronic disease, (3) Patient-centered care in chronic diseases, (4) Issues and barriers to achieve patient-centered care, and (5) Guide tool for health professionals’ training and education in patient-centered care.

2. Chronic diseases: the challenge of the twenty-first century

The World Health Organization (WHO) defines chronic illnesses as diseases of long duration and generally slow progression. These diseases can usually be controlled but not cured and include persistent and repeated health problems, gradual changes over time, and asynchronous evolution [4]. Many people around the world are seeing their lives being shattered and even shortened due to one or more chronic conditions [5]. Noncommunicable diseases such as diabetes mellitus, heart disease, obesity, chronic respiratory diseases, and cancer are among the most common [6, 7]. These diseases are the leading cause of death among adults, as well as mortality rates due to them in middle-aged people are higher in some high-income countries [8]. In 2012, about half of adult population had one or more chronic disease, and one of four adults had two or more chronic conditions [9]. Chronic diseases are major causes for disability, including chronic pain, motor and sensory dysfunction, blindness, lower limb amputation, and impaired functioning. In addition, chronic conditions are not only the principal cause for the increased costs in the healthcare system but also for the social costs, like absenteeism at work and decreased productivity [7]. Because of an aging population and the adoption of unhealthy lifestyles, chronic diseases are estimated to grow even further in the next decades. Therefore, it is not surprising that WHO considered chronic conditions the healthcare challenge of this century.

The principal causes of chronic diseases have been identified and well established. Age and hereditary are the only non-modifiable risk factors; in almost all developed countries, most common causes are modifiable, as unhealthy diet and excessive energy intake, tobacco use, physical inactivity, and alcohol abuse [8].

Chronic disease can impact quality of life and daily activities and should require ongoing actions on a long-term basis [10] (Table 1). Often, people living with chronic disease face significant life
changes and deal with constant threats to their personal health [11]. Most of them must manage daily symptoms, special diets, physical exercise plans, adherence to medication regimens, and systematic monitoring to identify new problems. Each person is affected in a different way by chronic disease; experiences diverge according to personal (e.g., coping strategies), contextual (e.g., access to health systems), and physical (e.g., symptoms) contexts [10].

As indicated in Table 1, patients with chronic disease face significant stresses in managing their illness [11] that go far beyond the functional impairments. Therefore, the major goal for healthcare system, and particularly for health professionals, is to address the needs of chronic patients and their care [12].

Nowadays, with effective behavior change efforts and adherence to medication regimens, chronic diseases and their consequences can often be better managed [8, 13]. However, the traditional paternalistic model of care focused on the control of acute symptoms shows itself inadequate to meet the challenge of chronic disease and particularly the needs of chronic patients [14]. A systematic patient-centered approach that enables chronic patients to play an active role in their condition management and in the decision-making process on a day-to-day basis is required [8].

### 3. The patient with a chronic disease

Patient adaptation to illness has been found to be associated with patient engagement to treatment [15]. Despite differences among patients, studies revealed that the majority of patients and families wish to be more active and involved in treatment decisions and procedures [16]. This involvement, the amount of information, and the development of competencies that usually came along with it may indeed help patients to succeed dealing with disease and treatment’s challenges.
Currently, chronic patients (and their families) are, mostly, their own primary healthcare provider. Although they receive support and counselling from health professionals, most patients live the major part of their lives outside of health institutions, they work and have their families. Regarding their illness, patients are expected to motorize their symptoms, to make decisions about adherence behaviors, often to follow complex treatment regimens, to make decisions about when they need to seek professional care, and to make necessary life changes to reach or maintain better health outcomes. Effective self-management is, then, considered critical to meet the needs of people living with long-term conditions. Self-management has been defined as “the care taken by individuals towards their own health and well-being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents” [17]. Some factors related to the patient have been repeatedly highlighted to influence the way patient’s cope with this challenges.

### 3.1. Patient literacy

Health literacy respects to the ability to read, understand, and act upon health information and has been associated with the skills for making appropriate health decisions [18]. Receiving clear information and education increases patient understanding of the disease implications. On the other hand, information about treatment procedures enhances patient’s auto-efficacy and self-confidence.

Three distinct levels or purposes of health literacy have been identified: *functional*, basic skills in reading and writing necessary for effective functioning in a health context; *interactive*, more advanced cognitive literacy and social skills that enable active participation in healthcare; and *critical*, the ability to critically analyze and use information to participate in actions that overcome structural barriers to health [16].

A systematic review by Berkman and colleagues to determine whether low health literacy is related to the poorer use of healthcare, outcomes, costs, and disparities in health outcomes among persons of all ages found that low literacy was associated with poorer health outcomes and the poorer use of healthcare services [19]. Association between good level of health literacy and treatment outcomes, patient satisfaction, and better quality of care was also found in recent studies [20, 21].

### 3.2. Patient willingness and motivation

Studies show that, in general, patients wish some degree of participation on their care [22, 23]. Nevertheless, despite the evident benefits, not all patients feel motivated to participate in their care, to adhere to medical recommendations, or to change lifestyles or health behaviors that are key stones for their treatment. Hibbard and colleagues, in a study with adults aged 45–97 years old with chronic diseases, found that only 22% adopted more involved and active behaviors to participate in their treatment, 12% do not think that they must play an active role in their own health believing that they are just recipients of healthcare, 29% do not have enough information or understanding about their clinical situation and their treatment, and 37% have the understanding but not the confidence to be more involved [24].
In a qualitative study that aimed to explore patients’ and practitioners’ views on factors influencing engagement in self-management in the context of multimorbidity, with a sample drawn from four general practices in Greater Manchester, motivation emerged as one of the three themes that captured patients’ and professionals’ views. In this study, motivation drew on understandings that successful self-management was partly contingent on patients’ belief and expectation that self-management would improve their health and how low mood can negatively influence patients’ capacity and sense of responsibility for self-management [25].

Regarding adherence, in a study focused in the relation between physiotherapist’s attitudes and patient adherence, Chan and colleagues found that patient’s treatment motivation mediated the relationship between physiotherapist’s autonomy supportive behaviors and rehabilitation adherence [26]. Increasing patient motivation through motivational strategies and motivational interviewing can be used to reduce resistance and improve the odds of achieving positive clinical outcomes among noncompliant/resistant patients [27]. Highlighting the importance of motivation on patient adherence [28], a meta-analysis of systematic reviews about the effectiveness of adherence interventions published between 1990 and 2005 found that interventions focused on behavioral interventions that used incentives and patient motivation were among the most effective to promote adherence.

3.3. Patient emotional disorders

Depression is frequently associated with chronic conditions and, if untreated, can adversely affect the course of the disease and limit effective treatment for the chronic condition [29]. For instance, depression was found in 27% of diabetic population compared with 17% in the non-diabetic population. Those patients with diabetes and depression experienced an impact with a large effect size on quality of life, as compared with those who suffered diabetes and who were not depressed [30]. In another study, depression coexisting with diabetes was associated with poorer glycemic control, increased risk of complications, increased healthcare utilization and costs, increased functional disability, and lost work productivity [31]. There is also some evidence that depression affects self-management. Patients with depressive symptoms (including subclinical depression) were found much less likely to gain in activation and in their self-management behaviors [32].

3.4. Patient resources

Social support refers to the degree to which interpersonal relationships correspond to certain functions of material support, affective, emotional, informative, and positive social interaction [33] and is a multifaceted experience that involves voluntary associations and formal and informal relationships with others [34]. Social support can buffer the negative impact of life events on health and positively influence psychosocial adjustment and self-management of chronic illness [35]. A large amount of studies found associations between social support and clinical and self-management/self-care behaviors [36], health-related quality of life [37, 38], and patient adherence to treatment [39]. Patient’s network for social support includes family and friends, social environment, and all health providers [40].
In conclusion, adaptation to chronic illness is a dynamic ongoing process that is determined by a complexity of factors. Evidence has shown that patients are decision-makers that may actively contribute to their own care. Patient literacy, motivation, emotional well-being, and resources play an important role on patient adaption and are important challenges for healthcare providers. These challenges are better attended within the framework of the patient-centered model of care.

4. Patient-centered care in chronic diseases

Chronic disease management demands the adaptation of the patient-centered care model to the changing patients’ needs. Hudon and colleagues developed a thematic analysis based on Stewart’s model of patient-centered care, based on articles published between 1980 and 2009. They found six major themes: (a) Starting from the patient’s situation, (b) Legitimizing the illness experience, (c) Acknowledging the patient’s expertise, (d) Developing an ongoing partnership, (e) Offering realistic hope, and (f) Providing patients’ advocacy in the healthcare system.

4.1. Starting from the patient situation

Chronic patient-centered care requires an extended comprehension of the patient’s situation. This theme included two subthemes corresponding to Stewart et al. dimensions exploring both the disease and the illness and understanding the whole person. Exploring both the disease and the illness means to discover the patient’s personal and subjective experience of sickness: worries, feelings, expectations, previous experience of care, health behaviors, and confidence with chronic conditions management, with the same interested as the biological dimensions like physical evaluation and laboratory results.

Understanding the whole person, as the act of being aware of the surrounding circumstances of patient’s life, implies the acknowledgment that chronic health meanings could vary with adjacent environments. Stewart and colleagues (2003) recognize that take into account various aspects of the patient’s personal and life context allowed health professional’s comprehension to the several factors that influence patient’s complex dynamic responses to chronic condition. Contextual factors could be proximal and distal to the patient. Proximal factors refer to immediate and specific categories and comprise family, financial security, education, employment, leisure, and social support. Distal factors are related with general and meta-context categories and include community, culture, healthcare system, sociohistorical period, geography, and the media.

4.2. Legitimizing the illness experience

Chronic patient-centered care includes attending to patient’s needs, worries, and emotions as grief over their previous skills and allows them to express their concerns related to their

Stewart et al. (2006) model included six components: exploring both the disease and the illness experience, understanding the whole person, finding common ground, incorporating prevention and health promotion, enhancing the patient-doctor relationship, and being realistic.
chronic conditions. By recognizing subjective perceptions and sensations of illness, health professionals formally acknowledge the reality of the patient’s experiences and allow the patient to feel that his definition of reality is confirmed [42]. Legitimation helped patient in his/her illness adaptation process and improve patient-health professional relationship. Lehman and colleagues show that patients with chronic fatigue syndrome report more psychological distress and dissatisfaction when physician failed to legitimize their illness [43]. This theme is one of the most important, when improving centered care is a priority.

4.3. Acknowledging patient expertise on his/her own life

One of the central premises of Carl Rogers’ patient-centered model is the idea that each patient is the world best expert on himself [44]. Patient’s expertise should be acknowledged and respected by the caregiver. In chronic disease, great management of the conditions depends on patient’s actions; therefore, all the interactions with health professionals should centered on patients’ strengths and challenges on running their disease condition. The development of self-management plans should integrate not only the health professional expertise but also the patient’s concerns, priorities, and resources. Usually, patients appreciate being treated as a full member of the health team, as this promotes their sense of control and empowerment [10]. This requires a new empowerment paradigm, with redefinition of patient and health professional roles [45].

4.4. Developing an ongoing partnership

Effective chronic disease management entails an ongoing partnership between patient and health professionals. Partnership refers to both a relationship and a process [10, 35] and promotes patient empowering to take control over his/her situation. Therefore, patients can be involved in their care as an active partner, helping to clarify symptoms and diagnosis, sharing decisions and treatments responsibilities, discussing treatment outcomes and alternatives, and agreeing on a treatment plan. This theme corresponds to two subthemes on Stewart and colleagues model: enhancement of the physician-patient relationship and finding common ground [41].

Mutual respect, trust, and collaborative action are essential ingredients to build and enhance the patient-physician relationship. Both patient and health professional need to feel committed to sharing power and responsibility [10]. In chronic disease, physical conditions and patients’ preferences and capacities change over time and determine the nature of partnership in which moment. On the other hand, continuity of care is an opportunity to improve the patient-health professional relationship, to empower the patient and to support during the most difficult phases of chronic condition. According to this author, an effective partnership depends on four factors: patient (e.g., stage of adjustment to chronic illness, self-esteem), adjunctive factors (e.g., family support, health service resources), communication process (patient and health professional verbal and no verbal skills), and health professional (e.g., attitudes related to own role, self-awareness).

Finding a common ground is the process by which health professional and patient range a mutual understanding and agreement related to chronic disease (the problem), goals and priorities in management and/or treatment of chronic disease, and roles to be assumed both by patient and health professional [41]. Patient needs, preferences, and beliefs should be respected always.
4.5. Offering realistic hope

This theme emphasizes on hope and support in the context of uncertainty or the inevitable deterioration of chronic conditions and contrasts from Stewart and colleagues (2006) being realistic issue. Hope has been identified as a key attribute required for patient adaption to illness and disability [46]. Giving hope tempered with realism allows patients to deal with uncertainty and promotes patient well-being and adaptation. Hope does not suppress negative aspects of the illness but includes and focuses on the positive, less negative, and possible developments that may be considered better outcomes or better patient quality of life [47].

4.6. Providing patients’ advocacy in the healthcare system

This theme is new considering Stewart’s model and relates to the health professional’s role in guiding the patient through the healthcare system. That means defending their rights, interests and safety. Often, chronic conditions are complex and patients need different levels of care (e.g., physiotherapy), support groups, and community services.

4.7. Over time

The six themes previously described comprise a longitudinal dimension. Patient’s situation could change depending on the disease course, life context, and illness experience. On the other hand, patients’ expectations, knowledge, and expertise in self-management of his/her chronic conditions could improve (or not) over time and influence patient-health professional relationship. As the disease progresses, values, goals, and preferences must be reassessed and discussed. Even health professional advocacy role should be adjusted to patient desires at a particular time.

5. Issues and barriers to achieve patient-centered care

The WHO (2005) recognizes the potential benefits of chronic patient-centered care but also identifies many challenges when applying this approach [16]. In fact, even when health professionals recognize patient-centered approach as an essential feature in clinical practice, they report difficulties in maintaining these behaviors during care. Personal and professional barriers need to be considered to carry on this challenge.

5.1. Organizational barriers

Time constrains, staff shortage, and work overload are frequently mentioned as major difficulties for a patient-centered care by health professionals [48]. In a study developed by West and colleagues, nurses acknowledge that lack of time frequently compromises their ability to provide clear and complete information to patients and their families, to give effective emotional support, and to offer the appropriate treatment according to patient’s clinical needs and safety [49]. The limited time available for medical appointment is also referred by doctors [50, 51] and patients [52] as a barrier to provide information about diagnosis and to discuss
treatment options. The impossibility to control physical environment features like temperature or noise can reduce the possibility of health professionals to comply with patient's specific needs during recovery [49]. In addition, a private space that guarantees patient's confidentiality and dignity during medical procedures is a condition difficult to offer in healthcare institutions [49].

5.2. Interpersonal barriers

The lack of a common acknowledgment about the relevance of patient-centered practices in healthcare among professionals’ team is mentioned as an important barrier [53]. The health team relationships and the conditions given to the staff to effectively consider patients’ perspectives appear to facilitate a more generalized patient-centered attitude. When clinical and personal information about the patient is shared by the health team, the health professionals have major opportunities to make stronger and more consistent decisions about the best interventions toward the patient [54]. A prior and clear definition of the clinical practice role of each health professional regarding patients’ care and communication seems to be very useful to overcome difficulties in applying correctly a patient-centered attitude [55].

5.3. Individual barriers

Several studies have highlighted specific health professionals’ beliefs and feelings as possible barriers to a more patient-centered attitude. The fear of leading with patient’s emotional distress has been identified as an important obstacle for the adoption of relational models that approach nurses from their patients [49, 56]. Nurses feel frequently that the emotional detachment from their work and their patients is essential to keep going emotionally and mentally healthy and to prevent stress and burnout [57].

The professionals’ perception of patient roles and responsibilities can also affect their intervention during the medical procedures. In a study presented by Jallinoja and colleagues, nurses and physicians identify patients’ willingness to make changes in their lifestyles in a chronic disease context as a barrier to treatment [58]. Pessimistic judgments or unrealistic expectations about patients’ abilities to make effective lifestyle changes can compromise medical actions based in promoting empowerment. In a systematic review about barriers to the adoption of a shared decision-making process by physicians, doctors perceived inability to balance patients’ preferences with the clinical guidelines available, and they are afraid that the implementation of a shared decision-making process leads to patients’ discomfort or threatens health professionals’ autonomy. Moreover, the perception that shared decision-making practices does not contribute significantly to better patient’s outcomes is identified as a possible difficulty [48]. Lack of motivation and difficulties in following a holistic approach are another two important problems referred by nurses.

The gap between the “ideal” academically taught and the “real” clinical practice can lead to the withdrawal of patient-centered attitudes and to the adoption of more traditional paternalistic models [59, 60]. During the academic internship and among recently graduated health professionals is evident some inconstancy in orientation assumed toward patients.
That is students and professionals range from focusing exclusively in accomplish procedures and tasks correctly, or accent primary in patients’ needs and worries [51, 61, 62]. The newness of the experience endorses lack of confidence and uncertainly, when students have to decide about the right action to implement in specific situations during healthcare [63], and gives more strength to students’ preconceptions and stereotypes about patients [62]. In this period, senior colleagues who have responsibilities in tutoring students in their first interactions with patients play an important role as models [64]. However, not always those first clinical experiences are properly supervised [65] nor patient-centered care orientation is defended and practiced by tutors [51, 60, 66]. In this context, students face problems in really translating patient-centered approach into nursing care, because poor or ineffective teaching strategies were used to training patient-centered care skills [67, 68].

5.4. Providing healthcare to specific chronic patient groups

Difficulties in effective communication and patient-centered attitudes seem to exacerbate when healthcare is provided to certain patient groups, namely, patients with intellectual disabilities [69], critically ill patients [70], patients with severe communication impairment [71], elderly [63, 72] and pediatrics patients [73], and cancer patients [55].

6. Guide tool for health professionals’ training and education in patient-centered care

Patient-centered care requires competences in communication skills. Nowadays, many medical schools recognize the impact of communication skills and use guidelines to teach and assess these competences during undergraduate medical training [74, 75]. The recent European consensus on learning objectives for a core communication curriculum in healthcare professions [47] states as key tasks: (a) build relationship and develop trust and rapport; (b) elicit information from the patient/problems and concerns; (c) consider the patient’s perspective of the illness; (d) give relevant information and explanations; (e) develop shared plan of care; and (f) close the interview and set up next meeting.

Considering the effectiveness of several earlier guidelines about communication skills training in healthcare professional’s education, namely, the Calgary Cambridge [76], the Four Habits Model [77], Kalamazoo Consensus Framework [75], REDE Model Skills Checklist [74], and the Health Professionals Core Communication Curriculum [47], we propose a tool aimed to systematize major dimensions of patient-centered care in chronic illness as defined by Hudon and colleagues into their specific core conditions and respective communication skills, with examples of interactions with the patient (Table 2).

Regarding methods for effective training and education of health professionals’ students, active learning and reflective learning seem to be the most effective teaching strategies [75]. At the start, core conditions and communication skills have to be explained [76], and evidence of their utility in chronic patient-centered care should be provided. In formal
1. Starting from the patient situation

Core conditions
Gather information: (a) encourage patients to tell story of problems in their own words; (b) explore both the disease and the illness means (scan how each problem affects the patient’s life); examine patient beliefs, concerns, and expectations. Enhance patient to talk and express feelings.

Skills
Use open-ended questions to initiate patient narrative. Identify patient’s problems or subjects that patients desire to discuss with appropriate open questions. Use SAVE (74) for Vital activities: How does chemotherapy treatment impact on daily routines? Ideas: What do you think of talking to our psychologist about the emotional impact of chemotherapy treatment? Expectations: You are going to finish your chemotherapy treatment today. What are your expectations about it? Worries: What worries you most about chemotherapy treatment side effects?. Listen attentively without interruption, facilitating patient’s responses verbally (e.g., yes; ah, ah; go on; mm-hmm; I see) and nonverbal (e.g., eye contact, facial expression) facilitation. Attend to nonverbal cues, checking out body language and facial expression (e.g., This seems to be a difficult problem of you…). Clarify statements that are unclear or need amplification, with more specify or yes/no questions (e.g., Could you explain what you mean by having two bad days?). Summarize patient narrative to verify understanding of what the patient has said (e.g., So, you feel very tired and you think that your tiredness is not related with the intense work period you have been involved, and give patient opportunity to correct or add information.

2. Legitimizing the illness experience

Core conditions
Recognize emotional cues and clarify the emotion (if necessary). Validate patient’s views and feelings, avoiding judgments.

Skills
Demonstrate empathy, showing interest and care in the patient experience. Communicate understanding and appreciation of patient’s feeling or situation, using SAVE (74). Support: We are going to work together to find better solution to control your pain. Acknowledge: The experience you describe during your back pain crisis sound overwhelming. Validate: It’s very common for people with persistent pain feel exasperated and discouraged like you do. Emotion naming: You seem more discouraged today than our last appointment. Use no verbal cues (tone, eye contact, and posture) that show care and concern.

3. Acknowledging patient expertise on their own lives

Core conditions
Recognize patient’s attributes and expertise. Reinforce patient’s skills and strengths. Determine how much the patient desire to be included in choices and decisions and clarify your own role as a supporter and a trustful information provider. Negotiate a mutually acceptable plan.

Skills
Use open-ended questions to encourage patients to talk about illness, their experience, and their sources of information (e.g., What do you think are the most difficult task of your treatment? Where did you look for information on your illness?). Listen attentively, allowing patients to complete what they have to say without interruptions. Use reflection, to acknowledge what has worked with the patient (e.g., I see you already exercised three times a day. It is very important for your diabetes to exercise) and/or his/her resources and strengths (I realize you are very motivated to change your diet and start eating more health food). Support patients, using clarification questions that help them to rephrase information that is unclear or needs amplification (e.g., You are saying that having to take that pill worries you. Can you explain a little more?). Express the importance of patient expertise by incorporating patient’s opinions, values, and needs in treatment plans (e.g., Based on your concerns, I think that we should change our initial plan. What is your opinion?).
Use negotiation, showing respect about patient’s needs, expectations, and objectives (What do you expect from this treatment?), asking questions and promoting answers that may clarify the object of negotiation (Can you explain what you meant by having difficulties in think about this diet?), providing information that allows the discussion of different alternatives, understanding patient limitations (e.g., the resources that are need to implement a specific treatment), highlighting shared points of view and showing pleasure in agreement (I am very glad that we agree on several issues about your diet plan), and arranging plans that recurrently reassess decisions and help to adjust them if needed.

4. Developing an ongoing partnership

Core conditions

Enhancing the patient-physician relationship

Reveal interest in the patient as a person. Develop trust and rapport, accepting legitimacy of patient’s views and feeling. Provide support adjusted to the stage of chronic illness.

Finding common ground

Focus on working collaboratively to meet patient goals. Provide reliable, clear, evidence-based, and individualized information that promotes sharing decision and responsibilities. Use adequate strategies to clarify patient’s doubts and to support patient’s decisions. Promote the sense of “joining together” with patients in supportive partnerships collaboration to meet patient’s goals. Promote patient’s sharing information and educate patients on how to reach information and how to motorize treatment outcomes. Develop and use systems to record, communicate, and monitor the implementation of patient’s preferences.

Skills

Enhancing the patient-physician relationship

Attend to patient’s privacy, confidentiality, and autonomy. Acknowledge difficult situations and challenges during the chronic illness stages, providing continued, willing, helpful, gentle, supportive care. Deal kindly with embarrassing and disturbing issues. Avoid interrupting and respect the silences. Avoid direct advice (You should…), impositions (You have to…), or over, not realistic tranquilization (I’m sure you are going to be fine.). Consider patient’s degree of understanding and language, avoiding jargons. Use BUSTER [78]. Be prepared: define a plan to manage for specific patient’s emotions and practice self-regulation. Use nonjudgmental listening. Six second rule: avoid escalation of conversation. “Tell me more” statements: Can you tell me more about that worry that you just mentioned now? Empathize and validate: It isn’t easy to talk about your illness, is it? Respond with a wish statement: I wish this treatment had been more effective.

Finding common ground

Provide information, tailoring information to what the patient wants and/or is able to know, using words that show that you prioritize patient information needs, thru categories (e.g., Let’s talk about medication side effects) and “7C”: clear, concise, concrete, correct, coherent, complete, and courteous [79]. Check if the patients would like more information; if necessary, provide writing or audio-taping information. Be sure that your information promotes patient’s understanding and skills for decision taking. Make suggestions, rather than given directives (e.g., I would like to make a suggestion about your diet) and encourage patient to make choices (e.g., Let’s talk about your alternatives. I think you have three options here…).
Check understanding by asking patients feedback or teach back, asking to, in their own words, tell what you have just explained. Be careful and try not to sound like you are testing your patient (e.g., We have been talking about your diet. What do you think is the most important information so far, as for instance? Could you explain it back to me? I really want to know if I was clear enough).

Encourage questions, stating, e.g., Your questions are very important for me and your process, and use open-end questions, eliciting patient’s preference and views in relation to treatment options (e.g., For you what are the main benefits of this treatment? What about surgery?).

Reinforce patients for achieving small successes encouraging them to raise expectations about self-efficacy and enhancing involvement in partnership (e.g., We did so well. Your effort was compensated. I know we can do even more.).

Provide education on patient treatment by modeling and/or delivering written information and instructions that promote patient feeling of self-efficacy and encourage patients to build their own capacity for self-management.

5. Offering realistic hope

Core conditions Being responsive to patients’ concerns emotions and suffering. Being honest and trustful, providing clear update and realistic information. Having a positive attitude toward the diagnosis, the treatment, and the care. Including patient education and capacitiation to decrease uncertainty.

Skills Promote patients’ control toward the treatment and their own quality of life by providing clear and realistic information that allows patients to reduce uncertainty and to be aware of different alternatives and new developments. Promote patients’ positive thinking by using positive talk.

Table 2. Guidelines for effective communication with chronic health patients based on patient-centered care principles as defined by Hudon and colleagues [2].

academic education, active patient participation can be achieved either by using actor-simulated patients (sometimes called standardized patients) or by engaging real patient to share their own experiences [80, 81]. Videos can also be used. One good example is the Database of Individual Patient Experience of Illness (DIPEx) [82]. These educational sessions should be an ongoing task in clinical education and must be carefully plan to give space to trainees’ reflection. Participants should be able to discuss the skills used and the impact of the trained skills on the patient on health professional and should have the opportunity to obtain feedback on their performance [83].

Moreover, learning and training communication skills should be an ongoing process during academic and professional education and meet the progressively more difficult demands that are placed on students and professionals. Thus, for example, basic communication skills such as welcoming the patient or developing empathy should be the focus of training in the early years. On the other hand, issues such as giving bad news or dealing with emotionally disturbing situations should be integrated into the more advanced years of training.

At the end of the training, participants should be able to use a checklist that helps them to verify if all dimensions of chronic patient-centered care model have been considered during their interaction with patient (Table 3).
7. Conclusions

In this chapter, we have described some of the challenges motivated by chronic disease management demands and outlined some core principles of patient-centered care in chronic disease. Promoting a chronic patient-centered approach is likely depending on giving primacy to the subjective aspects of illness, therefore is not a simple matter and must be included in all levels of medical education. Two important next steps concerning the development of chronic patient-centered model must be considered. First, training skills programs must be integrated in preclinical courses and not only in courses of communication as usually. Second, principles of chronic patient-centered model should be applied to a wide variety of chronic diseases, making them tangibly significant to concrete clinical conditions.

Author details

Ana Monteiro Grilo*, Margarida Custódio dos Santos1,2, Ana Isabel Gomes3 and Joana Santos Rita4

*Address all correspondence to: ana.grilo@estesl.ipl.pt
1 Higher School of Health Technology, Polytechnic Institute of Lisbon, Lisbon, Portugal
2 Faculty of Psychology, University of Lisbon, Lisbon, Portugal
3 Lusíadas Lisbon Hospital, Lisbon, Portugal
4 Lisbon Regional Health Administration, Odivelas Health Care Centers, Lisbon, Portugal

Table 3. Checklist for health professionals’ self-evaluation regarding communication and interaction with patients, based on patient-centered care principles as defined by Hudon and colleagues [2].
References


