

REVIEW ARTICLE

Patients' empowerment and the role of patients' education

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Abstract

Society has changed dramatically in recent decades not only from the demographic, social and economic point of view, but also from the educational aspect. The current population has higher levels of education than in previous times and can access information in a relatively easy way. In addition, the relationship between the healthcare professional and the patient has evolved from the paternalistic medicine to a more informed and participatory patient-provider relationship.

Patient participation and empowerment in the health decision-making process means that the patient has the opportunity to share his/her opinion, knowledge, experience and expectations with other patients, as well as with the health professionals in order to make informed decisions. With this evolution of the role of the patient in the current society, patients have asked for multidisciplinary and coordinated work among professionals to respond to their needs for diagnosis, control and treatment.

Patient's participation and empowerment can be conducted both, in the management of the disease, as well as helping to improve different aspects of health services. Participation and empowerment also mean representing other patients. In all cases, patients' education and training, using clear and plain language, and patients' confidence play a pivotal role.

The aim of this review is to present a summary of the scope of the situation regarding patients' empowerment and education.

Key words: Patient's participation, patient's empowerment, patient's education.

1. Introduction

During the last decades, society has changed not only from the demographic, social and economic point of view, but also from the educational aspect. Today, the general population has higher levels of education than in previous times and can access information very quickly. Although there are some exceptions, the patient today is a person interested in knowing what is happening to him or her, contrasting information, and discussing the different options with the healthcare professional. This patient is also encouraged to participate in the planning and development of health services (1).

There are many examples of how this more active patient can participate in the decision-making process regarding the management of health, as well as in the improvement of health services, health care centers and the representation of other patients (2). In addition, the relationship between the healthcare professional and the patient has evolved from the paternalistic medicine to a more informed and participatory patient-provider relationship. In this patient-centered care approach, healthcare professionals adopt a closer and equal relationship with patients, viewing them as partners (3).

2. Patients' participation and empowerment

Patient participation in the health decision-making process means giving the patient the opportunity to share his/her opinion, knowledge, experience and expectations

with other patients, as well as with the health professionals in order to make informed decisions. With this evolution of the role of the patient in the current society, patients have asked for multidisciplinary and coordinated work among professionals to respond to their needs for diagnosis, control and treatment. When patients participate in the decision-making process, they can exercise their fundamental rights and ask for quality in the services they receive. Information, communication and education are pivotal aspects for this participation (4).

A bibliometric review of the terms used in the last decade to refer to patient participation highlights the process followed when defining and understanding the meaning of this participation. Thus, at the 2002-2004 period, papers focused on compliance and adherence; between 2006 and 2009, the focus was on the relationship between participation and involvement; and from 2010, the majority of studies focus on empowerment (5). In addition, other terms have been used to refer to patients' participation, like patient collaboration, patient involvement, partnership or patient-centered care, among others (6).

To take part in this participation process with the professionals, patients need quality and understandable information that helps them make their decisions. Patients can also give us their opinion on the quality of the health services that we offer or on the characteristics of our organization. One more step in the participation process is to have the patient,

individually or in work groups, to improve a specific healthcare or practice process.

In addition, patients can be part of the so-called “stable participation bodies”. In the form of patient or family councils, they participate, in an on-going basis, in the quality improvement processes of the health care centers. Even, they can become part of the committees or governing boards of the institutions. This process of patient participation: information, consultation, collaboration, involvement and empowerment, constitutes the participation ladder (7, 8). In this ladder, patients develop different levels of participation both, at the individual level, in the management of the disease or in the improvement of health services, as well as at the advocacy level, representing other patients.

Empowering patients involves the collaboration of health professionals, policy makers and the community and means to provide people with the environment and opportunities to gather knowledge, skills, and confidence to become an active patient (9). The World Health Organization defined patient empowerment as the process by which people gain control over their own decisions related to their health (10). Furthermore, the concept of empowerment has been used in a wide variety of contexts, from health promotion to addressing chronic diseases, and in a multidimensional way (11). However, there is still no consensual definition of this term (12).

3. Patients’ education

Empowered patients should be persons with rigorous and truthful information about their clinical condition and about the topic of interest, in order to feel confident and able to make a decision or express an opinion safely. To reach this level, it is necessary to educate and train the patient in the task they have to perform, in the therapeutic plan or in the improvement of a care process. Patients’ education and training, using clear and plain language, as well as providing confidence play a pivotal role to improve health care outcomes (13). Patient education is an important aspect of patient-provider communication and share decision-making (14).

Patient health education is necessary to promote, achieve and maintain good health by actively incorporating patients in caring for their own health and autonomy (15). In this sense, health professionals should take into account the level of health literacy of patients to offer them information adapted to their needs that is easy to understand and assimilate. (16, 17). In addition, it is necessary to incorporate a change in the patient's behavior, so it will also be necessary to think about how to motivate him or her (18).

A strategy in this sense to ensure that the patient has understood the information is the use of the “teach back” method, through which the healthcare professional checks if the patient can answer three questions: what is wrong with me, what should I do and why it is important to do so (19).

There is great variation in the type of educational actions and programs for patients, as well as in their design,

implementation, environment and results obtained both, in terms of physical and psychological health, as well as regarding the use of health services (20).

Health education can be carried out through a set of training actions at the individual or group level that can be developed in health centers, or through more extensive and in deep programs. Among the different patient education activities, the Stanford University program was one of the pioneers in this area (21). Jointly with the expert patient programs (22) constitute an example of how empowered patients can be involved in the health decision-making process.

Since these programs began, the education of patients has evolved. At present, special emphasis is placed on aspects such as online training, as well as the evaluation of the results of said education (14).

4. The role of health professionals

Health professionals should understand, accept and motivate this new role in the patient in order to have a truly and effective model of participation and empowerment of the patient in decision-making. The established communication between the health professional and the patient is essential to create a climate of trust between both and to facilitate the patient active participation. This situation implies moving from a paternalistic relationship to a deliberative one, with greater equality between the two (23).

For this, it is necessary to share decisions between the professional and the patient. This is especially important for chronic

patients who require long-term and continuous care. Shared care supposes that the professional knows how to recognize the needs and values of the patient, ensures that they have sufficient and correct information, communicates and shows empathy towards the patient's situation, in a way that facilitates their participation and decision-making decisions jointly (24-26).

It is also necessary to educate professionals in the new role of the patient in decision-making in order to promote the existence of a relationship of trust and cooperation between them (23). There are some studies that show how to train professionals in specific aspects of integrated care (27); as well as in the actions to be taken to ensure that communication with patients is effective and in accordance with their needs and expectations (19, 28).

To have this deliberative patient-provider relationship means that patients have the necessary information adapted to their needs that allows them to speak in confidence about their preferences and make informed decisions. At the same time, health professionals feel useful accompanying patients in the decision making process. Finally, to achieve this deliberative patient-provider relationship, it is essential that both, patient and health professional are prepared and trained in the establishment of this new type of relationship.

5. Conclusions

The patient today reflects a person with a higher level of education and access to information than patients of other times. This situation leads to an active role of the patient in the health decision-making process. It also entails a change in the patient-provider relationship and communication.

Patient participation can be carried out at the individual level, in the management of the disease or contributing to the improvement of health services. In addition, the patient can also participate by representing other patients and advocate in the defense of their rights. There are different levels of patient participation in decision-making than range from having good quality information or answering surveys to collaborate and being involved

in continuous quality improvement actions. In addition, patient's empowerment means that the person, with information and experience, feels confident to make informed decisions.

Training is a key issue to empower patients and to participate in the decision-making process. Patient education has also evolved over time, from the earliest experiences of the expert patient program. Today, there is a great variety of actions and training programs for patients and professionals on how to empower the patient in the health decision-making process.

More research is needed to know the impact of patient education on the health status and the use of health services, as well as on ways to evaluate and measure these results.

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