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Evaluation of therapeutic patient education

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Abstract:

Over the past thirty years, therapeutic patient education (TPE) has become an essential part of the treatment of long-term diseases. Evaluations of this new practice are expected, and are sometimes imposed according to protocols and criteria that do not always reflect the complexity of changes taking place within patients and healthcare providers. Sometimes, expected results are not achieved because evaluation methods are inappropriate. These guidelines, drawn up by three university centres heavily involved in the development of therapeutic education, deal mainly with the principles and criteria of evaluation. Evaluation of therapeutic patient education focuses on patients, and those close to them, in the bio-clinical, psychosocial and pedagogical domains. It also focuses on healthcare educator teams, therapeutic education programmes and activities. Finally, it assesses educational structures, and examines prevention strategies on a local, regional and national level. Timescales needed for this evaluation are ongoing and lengthy, given that therapeutic education is a continuous process, and accompanies patients throughout the course of their illness. Finally, these recommendations are underscored by an ethics that requires that any evaluation of therapeutic education be fundamentally patient-oriented, in order to foster a partnership between the patient and the healthcare professional.
1- Introduction

Over the past thirty years, therapeutic patient education (TPE) programmes have been implemented for patients suffering from chronic diseases such as diabetes, asthma, haemophilia, cardiovascular diseases, atopic dermatitis, ...)

It is estimated that by 2020 chronic diseases, will be the leading cause of death and disability in the world (1). Management of these diseases now requires patients to become partners of healthcare professionals (2,3), and to be trained to deal with their own particular illness (4,5). Several studies demonstrate the beneficial effects of TPE, particularly in diabetes and asthma (6-12). In 1998, a working group of the WHO’s Regional Office for Europe, formed on the initiative of the three centres involved in this article, has contributed to the recognition of TPE as part of therapy and long-term follow-up of chronic diseases (13).

Whilst TPE now plays an increasingly important role in healthcare systems, evaluations are expected and occasionally imposed, without the direct involvement of the local healthcare providers as to evaluation protocols. This situation occasionally leads to decisions being made whereby the results obtained do not reflect the complexity of changes taking place within patients. Sometimes, expected results are not obtained because evaluation procedures are inappropriate (14).

These guidelines mainly focus on the principles of evaluating TPE. Whilst certain proposals concern subjects, criteria and indicators for evaluation, our centres’ initial aim is to share a methodological orientation and, above all, an approach whereby evaluation might be given its fundamental dimension, focused on training and learning.

2- Defining evaluation in TPE

In TPE, the term “to evaluate” is defined as follows: to collect relevant, reliable and valid information, to analyse said information and compare it to benchmark data or standards.

Evaluation should not be used as a medical, educational, institutional or social sanction, nor should it be used as any other form of reporting tool for excluding patients from the evaluation system.

In any evaluation, the main focus is on the patients themselves, since they play an active role in the decision-making process.
3-Principles of evaluating TPE

Evaluating TPE takes into account a series of multi-factorial and inter-dependent processes. Hence it falls within the framework of systemic thinking. Evaluation of therapeutic education relies on the use of criteria and indicators which take into consideration various dimensions: biological, clinical, pedagogical, psychological, social, organisational, economic and political.

These criteria and indicators evolve differently over time, a fact which must also be taken into account during the evaluation process.

Linking together these criteria and indicators, in terms of raising questions and taking decisions, is characteristic of evaluative thinking, which constitutes a global approach that goes beyond factual, partial and standardised evaluation procedures.

Evaluating TPE does not only mean measuring how many fixed objectives have been reached, it also involves measuring its effects on a range of transformations, which may, or may not, have been anticipated.

Evaluation is part of the educational process, and to this extent must be designed and incorporated at the very start of any education programme.

Patients must play a part in choosing time, conditions and tools needed for evaluation. Similarly, patients must systematically be kept and fully informed of results obtained from evaluations.

4 - Aims, criteria and indicators for evaluating TPE

- 4-1 Transformations in patients, their families and those around them

The purpose of evaluations is to highlight - both objectively and subjectively - the transformations taking place in patients, which manifest themselves according to various parameters (bio-clinical, psychological, social and pedagogical), and which affect the people close to the patient. Patients are called upon to produce criteria and indicators, like those produced by healthcare professionals, that will serve to establish certain benchmarks.

- The bio-clinical domain, in which “objective” proof is provided showing that biological or clinical changes have taken place, is based on changes in patients’ behaviour as a result of education. Here, the following indicators may be found: glycosylated haemoglobin levels in diabetics; body mass index in obese patients; blood pressure in hypertensive patients, etc. However, important bio-clinical evaluation may be (since education is after all a
therapeutic strategy), it cannot claim to be the sole proof of effectiveness.

- **Evaluation in the pedagogical domain** ensures that learning has taken place among patients, which provides them with the necessary competencies and the potential to effect change at a later date. It is important that several aspects are assessed: how patients’ knowledge is constructed and organised; the confidence that the patients have in their knowledge; understanding of medical terminology and physiological phenomena and mechanisms; analysis and interpretation of clinical signs and scenarios; problem-solving; the ability to take decisions that will not jeopardise health. A better understanding of oneself and one’s needs is also important as well as a better use and management of health care. In addition, patients must be able to master self-monitoring and treatment techniques.

Education also leads to a development of patients’ perceptive skills, i.e. the ability to interpret more accurately and analytically those messages transmitted by the body. This awareness - developed by the patient with regard to all aspects of knowledge - is known as metacognition. The patient’s ability to manage several types of emotions can also be legitimately considered as a result of therapeutic education.

The patient’s satisfaction levels and the perceived usefulness of the education programme should be systematically measured. Lastly, the revival of a project that was cancelled due to the patient’s preoccupation with his/her illness or, conversely, the emergence of a project due to the belief by the patient that he/she is now more capable of managing his/her condition, represents one of the main criteria for the effectiveness of TPE.

- **Psychosocial evaluation**: Here, changes in attitudes towards health are evaluated, along with changes in causal attribution; development of self-image, self-esteem, perception of self-effectiveness; improvements in the quality of life. Moreover, attempts are made to ascertain whether therapeutic education has helped patients to take more control of their lives and illness.

The social interface - and in particular changes made by the patient to transform the ‘family’ environment into an environment open to care - represent a new dimension in evaluating TPE. This might be evident when patients pass on their knowledge to others or initiate changes in their home lifestyle.

4-2 Change in attitudes of healthcare providers
TPE, as well as promoting the involvement of new healthcare players such as patient associations, brings profound and lasting change to the values and roles of healthcare teams.

These changes in values and attitudes affect both the view that healthcare professionals have of patients, and the relationship they develop with their patients.

Hence, healthcare professionals should consider patients as capable partners, who have a refined knowledge of their individual illnesses. In this respect, it is important for patients to set their own health benchmarks, if such therapeutic alliances are to succeed.

Finally, it is the principle of patient self-determination, accepted by healthcare professionals and teams, which determines how the latter regard the purpose of TPE. This principle of self-determination comes under the more general movement of “empowerment”.

4-3 Therapeutic education programmes and aids; educational activities.

The evaluation of educational programmes must include a detailed description of the programme concerned, theoretical references used and its goals and teaching structures.

Steps must be taken to ensure that the programme is:

- formalised, and repeated regularly;
- presented and explained to the patient, and sent to the attending physician and health professionals concerned;
- tailor-made to meet the needs of individual patients (educational diagnosis);
- integrated into existing care and therapy;
- adaptable and multi-layered (patient groups, individual consultation, distance learning, etc).

It should also make use of aids, documents and tools, relevant to patient skills.

4-4 Educational structures and coordination with existing therapy

Here, the aim is to evaluate how effectively educational programmes are inserted in the healthcare institutions in terms of bringing about preventive change.

- Issuing a therapeutic education policy statement.
- Guaranteeing that therapeutic education is accessible to all patients via the use of information technology, including new educational and communications technologies.
4-5 Prevention strategies and savings on healthcare

Both on a regional and national level, it is acknowledged that TPE forms part of a policy that takes into account the medium - and long-term - benefits of secondary and tertiary prevention.

Evaluation criteria may - for example – focus on the net effects of therapeutic education; Epidemiological (morbidity, mortality ...) Economic (hospital readmission rates, better compliance ...), Social/societal (reduction in school/work absenteeism), Political.

Conclusion

Therapeutic education is a new fundamental dimension in healthcare that has yet to be evaluated. By its very nature, it differs from more traditional forms of intervention (pharmacological, surgical, therapeutic); instead, it forms part of another philosophy, which places the patient at the centre of the evaluation process. Hence, it takes into consideration other criteria, within a broader scope that simultaneously combines bio-clinical, psychosocial and pedagogical domains. This evaluation accompanies patients throughout their lives and takes into account of the dimensions of the transformations which take place in each of them.
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