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PERSPECTIVES

The utopia of research: epistemology of patient education

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This is not a science like any other: it cannot be communicated in any way, but like the flames that spread from a flickering fire, a spark that suddenly emerges from long discussion sessions on the issue and a life shared with others, it can take strength from itself.

Plato, Letters VII in Works.

Introduction

Traditionally, researchers have thought of chronic illness as having a course that waxes and wanes but patients who live with the disease may not have the same point of view [1]. In particular, chronic illness has an ever changing perspective that challenges patients to give meaning to their experience [2]. The person with a chronic illness lives in a double dimension of remembered health and current disease, so that the measure of wellness is determined by comparing the experience of what is known and understood about illness and vice versa [2–4]. Consequently, such a perspective of chronic disease contains elements of both illness and wellness. It involves beliefs, perceptions, attitudes and experience of what it means to be permanently ill in a particular context [2–5]. For a patient needs to monitor his/her own health status, take the medication prescribed, interact with healthcare providers and manage the impact of illness on physical, psychological, and social levels. As the reality of such experience and its personal and social context changes, people's perspectives shift to the degree in which illness is in the foreground or background of their world. The perception of reality, not reality itself, is the essence of how people interpret and respond to their chronic illness [2–5]. Patients are always shocked by the deafening silence of those around them. Healthy people cannot gauge a form of anguish so alien to everyday experience. If they have never descended to the depths of lupus or leukemia or depression, how can they possibly know what it is like? The sick inevitably feel alone, both when they are literally alone and when they are surrounded by family and friends. As David Biro wrote "Their world is both removed and running on a different clock. Time becomes severely distorted, typically slowing down, anguishingly so, as patients wait for test results, a dreaded checkup, or an MRI scan that will reveal who knows what. Or time keeps repeating itself, replaying our pain and discomforts, conversations with doctors, fears about the future, over and over again. For the healthy, by contrast, time sails on without a hitch; it flies" [6].

These shifting perspectives are due to the erratic course of the disease but also to psychological dimensions [6, 7]. Whether a person engages in health promotion activities such as exercise or living with asthma or diabetes, he or she is responsible for daily management. This is as true for health as for disease. Whether one decides not to engage in healthful behaviors or not to be active in managing a disease, the decision reflects a personal style in life. Except in the case of a person who is completely ignorant of healthful behaviors, it is unthinkable not to manage one's health, the only question is how. The issue of self-management is especially important for people with a chronic disease, as only they are responsible for their own care. With this in mind, self-assessment of symptoms is coupled with personal perceptions of ability to cope with the disease [8]. The disease not only damages organic and functional aspects of the body but, often with different shades based on the specificities of the patient, it substantially affects social, emotional and relational aspects both in the family and at work [9]. It sometimes cuts into how one interprets life itself and orders existential priorities [10]. Within this paradigm,

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self-management should help patients to keep mental and physical health in their sight [10, 11]. For most of them, self-management is a lifetime task that involves continuous actions of self-care which, in turn, require new meaningful behaviors and life roles in different conditions [10–13]. Furthermore, dealing with the emotional challenge of having a chronic condition alters one's view of the future. Representations of disease and the meanings attributed to it, as gathered from the stories of patients, are not only subjective but also have social meanings that result from a stratification occurring over time in the form of personal beliefs and cultural traditions [14]. Patients and their families carry specific cultural ideas and values related to concepts of health, reporting of symptoms, expectations on how care will be delivered, and beliefs about medication and treatments [15]. Culture-specific values also influence patient roles and expectations about how much information on illness and treatment is desired, and such values guide the processes of decision-making [16]. From the literature, and from real life stories from my own experience, it becomes clear that the person with a chronic disease needs valid and effective help to prevent his/her illness from getting the upper hand in life.

Evolution of some useful concepts

An evidence base for patient education has developed over the last few years as a means to prevent and treat chronic diseases more effectively. The stages in the development of patient education can be related to specific time periods and mirror cultural changes in society. There was a time when the physician was the authority, responsible for diagnosing, treating and the healing of patients. Even when they did supply health information to their patients this was frequently not part of a structured health promotion plan [17]. The patient was viewed as passive and not even expected to ask any questions. Health care professionals were the experts who could decide what was right without checking the patient's wishes or preferences. Gradually, more emphasis began to be placed on educating patients and supplying individual information [18]. Early in the 1970s, patients were still not active players and those who did not comply with their provider's recommendations were thought of as deviating and behaving irrationally [19]. The concept of compliance, for example, implied a dependent lay person and a dominant professional. Later, adherence to medical treatment was based upon pre-conceived beliefs about the appropriate roles for patients and professionals [18]. In 1998, the World Health Organization recognized that Therapeutic Patient Education (TPE) is a significant contribution to chronic disease management that should be incorporated into health care professional training programs [20]. TPE is based upon the powerful concept that educating patients to develop skills to better manage their disease and adapt their lives to it contributes to health. Patients were now engaged in the promotion of their own health and in making choices in treatment and treatment goals. This is important because most of the time they are not in touch with their health-care providers and must provide for themselves. In addition, social inequalities play an important role in the provision of health care, and action to address them should be implemented at a systemic, not only individual, level. Despite the statement by the WHO and the initiatives that followed, a recent article that analyzed the difficulties it encountered over time in the treatment of diabetes and what solutions may be useful to implement existing educational models in Europe, defined TPE the "Cinderella" among health interventions [21]. The paper reported on such interventions as the Insulin Treatment and Teaching Programme in Germany, Austria and Romania, the DAFNE trials in the UK and Ireland, the DESMOND and X-PERT programmes in the UK [22–25]. Nevertheless, TPE continues to remain a low-status discipline and one unworthy of much attention, perhaps because the tendency in medicine to emphasize quantifiable biomedical outcomes over patient-oriented ones begins in medical school and patient education may not blend well with reductionist science [26].

Focus on patient education

As observed by Bodenheimer et al. [17] one may distinguish between traditional and collaborative care. In the former, patient education imparts disease-specific information and technical skills. For example, patients with diabetes are informed about diet, exercise, and medication and learn the technicalities of blood glucose monitoring. However, professionals remain the ones to decide what to teach. In collaborative care, in contrast, self-management education goes further, in that it focuses on problem-solving skills. An important concept in self-management education is self-efficacy, the confidence that one can carry out a behavior required to reach a desired goal. Patients learn to identify problems from their own point of view and to find solutions [17]. One can argue that teaching self-management education may be more effective than 'information only' models in improving clinical outcomes. Initial studies showed that a self-management education program bringing together patients with a variety of chronic conditions may improve outcomes and reduce costs [17, 27]. Self-management education is challenging because it requires both quantitative and qualitative methodologies from multiple disciplines and consideration of patient-oriented and psycho-social outcomes on top of traditional biomedical outcomes. Patients are actively involved in the learning process, whose determinants and objectives depend on them. Self-management

education is influenced by individual patient characteristics, their context, the presence or absence of supportive relationships, the health care system, cultural aspects and the prevailing economic conditions [21]. In the same way the history of the patient, the meaningful events in his/her life, language, representations of illness, ways of tackling problems, all form a background to his/her 'alliance' with the physician and other potential stakeholders. The meaning of the disease is configured through a dialog between the care providers and the patient. At this point it is useful to remember that health care releases about patient education note that diabetes self-management is a complex process that depends on much more than the actions, attitudes and beliefs of professionals [21]. The context in which the patient and the providers are placed also includes the life stories of both. In this sense, the therapeutic relationship becomes a meeting and a dialog between two sets of experiences. In an educational dimension, this is more than mere offering of advice. Rather, it should be seen as a complete approach from planning to consultation.

A wide variety of issues related to self-management education and the restructuring of team work aimed at treating type 2 diabetes were at the core of a number of systematic reviews and meta-analyses [27–30]. Type 2 diabetes is a chronic condition and typically requires varied and complex treatment programmes. Substantial evidence indicates that lack of adherence to and persistence with therapy are some of the limiting factors in the drive to achieve and maintain desirable management goals. Factors that impede adherence include treatment choices, administration regimens, clinical inertia, communication deficits, and barriers of trust and belief [31], all issues that should be addressed within disease management. The educational setting is paramount to develop positive attitudes towards treatment and life [32]. Analysis of feelings and needs encourages patients to share concerns about their illness and self-concept issues [33]. An accurate reading of the definition above shows that education is a long process which requires a team of educators to provide the best opportunities for improvement in patient outcomes. New models and working strategies must be found to meet the growing needs of diabetic persons while, at the same time, offering high standards of care and effective use of resources. Basic knowledge is very important for the patient but the reinforcement of appropriate attitudes and a continuous process of motivation is central to change habits and behaviors [33].

For persons with Type 1 diabetes, educational and psychological support is needed to manage multiple daily administrations of insulin and to monitor blood glucose, dietary intake and energy expenditure. These patients may cope either by adjusting their social role to fit the demands and challenges of diabetes or by trying to readjust their experiences viewing their situation in a more positive light [34]. Assessment of a patient's expectations, building the relationship, working with families, minimizing barriers to care, and formulating treatment plans and goals must constantly be provided by operators and their parent organizations. All stakeholders require access to reliable information, support and opportunities for participation in decision-making [34]. In our experience, providing support to patients with type 1 diabetes means helping them build the future with a focus on both clinical and emotional dimensions [34, 35].

Late complications of diabetes can be avoided or at least delayed using available therapies but the percentage of patients achieving the targets proposed by professionals is still too low [36]. Ideally, people with diabetes or any chronic disease have to be involved in their own treatment [37]. In TPE the patient is no longer the object but instead one actor in the process. He becomes part of the team and part of the solution. The patient takes care of himself and will, step-by-step, become aware of the consequences of his actions, in collaboration with his health team [37]. However, the literature reports that, whilst diabetes-related knowledge has reached high levels in patients, "stagnant perceived risk" suggests that people at risk are not applying this knowledge to themselves [37].

Epistemological aspects

The experience of education reveals that its nature has to do with impossible human completeness, in which the individual agrees to test himself in the hope of successfully managing the future [38]. This focus on the future and future emancipation is even more awaited and sought after when the person has an illness. The desire for change aims at rediscovering well-being and integrity. For this to happen a person has to be shown how to be autonomous despite the disease.

Looking beyond the matter of a patient's life, one must consider the training of health workers and its consequences on clinical outcomes [39]. Studies of implicit messages in medical education have discussed how these may negatively influence trainees' epistemic cognition and thus humanistic patient care [40]. The authors argue that integration of humanities in medical education can promote "a tolerance for ambiguity, provide a basis for the reconciliation of competing values, and foster the ability to discern the narrative thread in the setting of illness" [40]. The need for new instruments and methodologies to study epistemic cognition settings and its relationship to clinical outcomes has also been identified [41].

Medical education and its practices have implications that relate to epistemological beliefs and humanistic patient care [41], so that future areas of research should include the development of theoretical frameworks and

new methodological approaches able to examine epistemic cognition. To foster an integrative and humane approach to medical practice, humanism should be incorporated into medical education along with epistemic cognition, as the two appear to be interdependent endeavors [42]. At present, medical students are influenced by implicit messages that what patients report may be unreliable, which is instrumental to preserve a physician's authority. Evidence-based medicine often fails "to acknowledge the extensive social, economic and even political roots of the dilemmas faced by doctors" [42]. Some authors have pointed out that evidence-based medicine prioritizes experimental above experiential knowledge and that, consequently, the notion of knowledge translation eclipses the view of medical knowledge as socially negotiated, value-laden, or built from experience [43, 44]. All of the above suggest that specific pedagogical approaches should be researched to enhance epistemological development in medical education [45]. These may include "integrating first-hand patient experience early in the curriculum to encourage the understanding and management of uncertainty, incorporating problem-based learning to enhance relativistic epistemology, and providing physicians with tools and resources for judging and interpreting medical information" [46]. Others have highlighted the need for explicit and reflective approaches to teach such epistemological aspects of medicine as uncertainty, subjectivity, and authority in the light of messages that are implicit in the medical context [47].

As medicine became increasingly scientific, it sought to separate itself from its humanistic dimension. This was felt necessary to establish the claims to truth that underlie scientific authority. According to Wasserman, it was generally accepted that "if medicine remained an intuitive or interpretive art, then its authority would be weakened" [48]. Because of this, the physician's intuitive expertise has been restricted to those areas where science has not yet been able to define the mechanistic causes of disease. Where science has not proved that one diagnosis or treatment is superior to any other, the physician is allowed to be something of an artist, using the specific social context, patient attributes and values to guide care [48]. Even so, clinical conduct moves along the tenets of the biomedical model. The evolution of medicine toward an increasingly scientific episteme has generated perplexity from outside and within the medical profession. The debate about evidence-based medicine [49], with some of its reductionist versions expecting to diagnose and treat individual patients based on population-derived likelihoods, is ongoing [50]. Certainly, medicine has come a long way from the "boys in white" era, but this sort of attitude remains at the basis of many clinical difficulties [51]. Problems in doctor–patient communication, for example, can be interpreted as stemming from the increasingly smaller role for patient individuation against biomedical symptomology. When overstressed, this direction of medicine, overlooking the individual person, produces a didactic clinical pedagogy, a lecturing approach to patient care that has often been noted in the sociological literature. But sociocultural influences are often ignored in clinical practice despite their strong social components.

Medical training should include robust artistic pedagogic approaches, so that physicians learn to work with patients rather than didactically on them [45, 48]. The purpose of the latter approach is reduced to assisting the doctor in being culturally sensitive, identifying the appropriate ways of talking to patients to explain and implement a priori medical knowledge. Doctors do recognize human variability among their patients and tailor their language accordingly but, when guided by the primacy of universalized science, the clinic remains a didactic environment where the physician instructs the patient with a paternalistic, top-down style. Patients communicate with physicians only if the doctor needs somatic information, while the social context is considered marginal to symptoms and signs. Where social science or even basic social skills are used in the clinic, they are employed as a lubricant to enact cures on a body, and much less often as a necessary methodological component of the diagnostic and treatment process itself. In traditional didactic education, students get ahead if they are able to adopt the teacher's point of view and fail if they cannot [48, 51, 52]. In medicine, patients who do not fit in with the physician's expectations are deemed failures, i.e., the "difficult", "noncompliant", "ignorant," "uneducated," distrustful patients that doctors meet every day. However, such patients can also be seen as culturally or even ontologically disenfranchised from a scientific clinical practice that lacks an artistic ability to identify and work with them as legitimate, autonomous human selves. Since this problem stems from the art-science disconnect within clinical medicine, social science is ideally suited to address it, although differently from the way it has done so far.

Training and development of the health workforce remain a strategy for making headway towards the goal of improved cultural competence in health services and systems and foster better patient involvement. For behavior change to occur, participants often need to consciously reject previous ideas and beliefs and transform their way of thinking. Transformational learning is a process that promotes deep emotional responses, leading to cognitive and behavioral change, potentially facilitating rich learning experiences and furthering knowledge translation [52]. Based upon our own experience, transformational learning can be induced and sustained with structured intervention models that last at least 4–5 years [32–35, 53]. Reflective responsibility not only concerns the patients' real experience but also the professionals' education and expertise. It is a responsibility that consists in recognizing the importance of thoughts, but

also feelings, relationships, and deontology in the caring process, all aspects that allow professionals to account for their actions as a whole [52]. This educational approach will facilitate healthcare providers' cultivation of an attitude to caring for their mental, relational and emotional life, preventing demotivation and burnout, and promoting personal and group well-being, through multidisciplinary practices. Healthcare professionals need to increasingly embrace an epistemology of reflective practice and an approach to education that recognizes and values the issues of meaning arising from practice-based knowledge. This may constitute a troubling and controversial field, but, nonetheless, an extremely rich and stimulating one.

Promoting experiences that educate professionals in reflective competence and support them in understanding the constructive values of their working experience [53] is the challenge, almost the utopia, of pedagogic research. Our aims are to educate professionals to recognize the different dimensions of their reasoning, enable them to elaborate emotions that derive from the role they have in the caring relationship, and learn to contextualize their actions in caring frameworks or pragmatic dimensions.

I have learned that time, training, competence and patience are needed to listen to people. It means accepting the complexity of human condition when struck by disease. If we truly wish to improve the lives of the sick, we must listen to them. As Livingstone observed, "An education is incomplete unless it leaves people with a philosophy of life, and never was this more needed than in our age of uncertainty" [54].

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Compliance with ethical standards

Conflict of interest The author declares no conflict of interest.

Ethical approval This article does not contain any studies with human participants performed by any of the authors.

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