



Therapeutic Education

10

Claire Llambrich Molines

Among the people who carry out work that directly or indirectly contributes to care provision, the patients themselves are a class of workers who are rarely identified as such. They hold no professional title; the tasks that they accomplish most often go unnoticed, although paradoxically the work is often taken for granted and expected; and of course, the hospital does not pay for it. In fact, the greatest part of this work remains invisible to the professionals [...], either because they do not see it being carried out or because it is not defined as work.

Strauss (1982) [17]

Abstract

Today, people suffering from cancer will live with the disease until the end of their life. Education provision for these people is a necessary complement to care provision. This corresponds to other theoretical models from the sciences of education, psychology and sociology that are distinct from the clinical models of evidence-based nursing and evidence-based medicine. This complementarity offers a holistic approach to sick people, and to familial and social ecosystems, and enables the empowerment of patients who accomplish their patient work, raising awareness of this work and assigning it a social value.

Keywords

Therapeutic patient education (TPE) · Cancer · Teaching · Support · Patient work

C. L. Molines (✉)
Institut Curie, Paris, France

© Springer Nature Switzerland AG 2019
F. Charnay-Sonnek, A. E. Murphy (eds.), *Principle of Nursing in Oncology*,
Principles of Specialty Nursing, https://doi.org/10.1007/978-3-319-76457-3_10

159

Introduction

Contemporary medicine is currently undergoing a transformation. Health professionals who are trained and shaped to cope with situations of acute care know how to cure. Chronic disease by definition cannot be cured. When it is not possible to cure people, how can we care for them? The caregivers are coming up against this new challenge to support patients in taking back control of their decisions, projects and lives that have been momentarily or permanently transformed by cancer. We can see that there are different stages for people with cancer and that even when they are cured they still need support. This experience of the disease inevitably affects everyday life.

The knowledge the patients gain from the experience of the disease often escapes the caregivers. Their subjective experience enables the patients to constitute a sum of knowledge, part of which remains private and out of reach to the care staff.

Who is the expert in this story? The patient as the subject who has experienced the disease or the health professional whose status is legitimized by a society that possesses a piecemeal and subjective medical and health knowledge? Is acculturation possible? Yes, if we consider that evidence-based knowledge of medicine is as important as lay knowledge acquired from the unique experience of the disease in the broad sense. Since the biomedical paradigm is correlated to a task prescribed for the action and being of the patient, the task is necessarily redefined by the patient and realized by incorporating new knowledge enabling an adaption to the psychosocial reality of the disease. Thus, the acculturation of the actors is not only possible but necessary, with a view to providing optimal support for patients suffering from cancer.

Linking evidence-based knowledge, based on “evidence-based medicine (EBM)” or “evidence-based nursing (EBN)” and lay knowledge acquired through the decoding of activities actually undertaken or experienced, enables a considerable enhancement to the thesaurus of the possible solutions in response to a situation of care. Therefore, to better perceive what the cancer is, it seems important to enable patients to use their knowledge, in particular that gained from experience, and to acquire new knowledge, from “EBM or EBN” but also from sociological, anthropological and psychological ways of thinking. TPE makes this possible.

In the first section, we will examine therapeutic patient education and its foundations. Then we will present the example of a therapeutic education programme put in place by a team of nurses in a Parisian anticancer centre. Lastly we will present the changes in the social roles that the implementation of such a mechanism can produce which re-examines the role of each actor, from the patient to the caregiver.

Therapeutic Patient Education, A Springboard Towards Autonomy

Definitions

According to the World Health Organization: “therapeutic patient education must enable the patients to acquire and retain the capacities and skills which help them to live with their disease in an optimal way. Therapeutic education therefore aims to

help patients and their families to understand the disease and the treatment, to cooperate with the care staff, and maintain or improve their quality of life” [20]. “The Cancer Patient Education Network” (CPEN), affiliated to the “National Cancer Institute” (NCI), complements this definition by specifying that “patient education permeates all the aspects of the experience of health care and consequently is an essential element in the continuum of care of prevention, detection, diagnosis, treatment, research, life, survival and end of life. Patient education aims to:

- Improve the patients’ understanding of their disease.
- Improve the patients’ understanding of how to manage several aspects of their disease.
- Improve the patients’ self-defence to act independently but in interdependency with their health care providers.
- Increase the patients’ motivation to comply with the treatment schedule by means of communication with suppliers.
- Improve the patients’ results and prevent or reduce complications.
- Help patients make informed treatment decisions.
- Improve patient use of the medical services by decreasing pointless telephone calls and recourse to the hospital.
- “Increase patient satisfaction with the health service and reduce the risk of professional misconduct” [1].

It appears important to add an additional dimension to these goals. Indeed, when “the patients are no longer the object but the subject of the care provided to them, then the objective is no longer to fight disease but to promote health and the process of prescription gives way to a process of education” [16]. During the course of health promotion, patients should be understood as thinking subjects who act according to their unique perceptions of the world. Thus the tools used in TPE come from psychology, communication and teaching. If people are considered as the author of their lives, then they need to develop emotional and psychosocial skills as a precursor to mobilizing skills that enable decision-making and action.

Techniques and Biases

The Support Relationship

Based on the principles set out by Carl Rogers [15], and on the transformation paradigm described in nursing sciences by Newman, Sime and Corcoran-Perry in 1991 [11], and used by Pepin, Ducharme and K  rouac [13], the practice of TPE is based on mastering the support relationship by mobilizing the technique of active listening [4]. The objective is to provide a serene space for the patients by promoting understanding of their representations of the disease, the treatment and their needs, values, resources, skills [5] and cognitive mechanisms. For this communication technique, the professionals must master the following techniques: listening, non-judgement, reformulation, valourization and questioning through non-inductive open questions. Managing the techniques of the support relationship is

indispensable at all levels of intervention in TPE. The caregivers must work on their position and means of communication and respond to their philosophical biases that can be difficult to change. This repositioning requires significant work on oneself.

The effect of this communication technique used in psychology proves to be therapeutic in terms of psychological care which can be used to provide support and help with progression. In addition it can manage shock and anxiety, aid with decision-making and raise awareness of the interior process encouraging empowerment, the feeling of self-efficacy and self-esteem and others. All these levers can be used to develop oneself and to take back the power to act on the situation. The support relationship is a reassuring framework allowing the creation of quality of life and emancipation [19].

Education

One of the founding principles of the educational position is to “think the other person capable” in the manner of Socrates (around 490-399 B.C.) who, using maieutics, postulated that each man already possesses knowledge and that the role of the teacher, who himself knows nothing, is to facilitate the emergence of this knowledge. This philosophical position is not that easy to integrate. Indeed, this is not a case of simply knowing that one should “think the other person capable” but of unconditionally and intuitively “thinking the other person capable ...”, thus nourishing the trust of others to enable the person to think of him/herself as capable of acting.

Therapeutic patient education essentially relies on five main pedagogical currents: However the last three are mostly the teaching foundations on the TPE.

- Frontal or magistro-centrism teaching: This is the transmissive model of accumulation of knowledge and authority.
- Behaviourism (or behaviourists) described by Watson and Pavlov. This concerns operant conditioning.
- Active or project-based learning, where the reference authors are Freinet, Dewey, Decroly and Oury, is based on learner experimentation.
- Cognitivism is a trend in which the learners mobilize the knowledge that is appropriate for a situation by drawing from their resources and stored knowledge.
- The fathers of the constructivism and socio-constructivism trends are Piaget and Vygotsky, respectively. They postulate that the truth does not exist. The learners construct their reality themselves. Here the information is restructured according to each person’s own reality.

In line with these great theories, teaching and learning methods have been developed following different modalities in accordance with the targeted objectives and the representations made by the teachers of the cognitive processes engaged in the learner.

Marcel Lesne [7], in his work compiling the existing educational methods, proposes a classification of three categories that he calls the modes of educational work (MEW): MEW1, MEW2 and MEW3 correspond, respectively, to the transmissive mode, the incentive mode and the appropriation mode. For each of these, Lesne

defines the status of the learner and that of the teacher and the social effects in terms of the type of social individual that it constructs. This model is a “tool of clarification of action” [7].

- The transmissive educational mode (type 1) is learning with normative orientation. In this mode, the learners are the *objects* of learning. The teachers possess and transmit their knowledge to the learners. They are recognized as legitimate; they control and sanction. “They accept and exercise the educational authority involved in any act of training” [7]. The educational methods used in this type of work are affirmative methods (teaching the model, demonstrative), interrogative methods, methods known as active, lectures, study of problems and mental training. The principal agents of this type of mechanism are instructors, teachers, lecturers, specialists or holders of a professional power. The social effects of such a mode of education are to prepare individuals for given roles, to close the gap between the individual behaviour and the general requirements of society. More generally, this creates individuals capable of reproducing social models. This MEW is the easiest to use for health professionals.
- The type 2 mode of educational work is an educational mode with personal orientation. The teachers are no longer holders of knowledge. They put the learners in a situation that enables their knowledge to emerge. The learner is *subject*. The individual’s creative forces are mobilized by the trainers who establish a dynamic of learning and seek to strengthen the autonomy of the person by encouraging free access to the different sources of knowledge. They explicitly refuse the qualitative power and control that manifests either in the form of self-evaluation or comes from the group. The agents of this mechanism are facilitators capable of creating favourable conditions for learning. This type of education creates individuals who are socially adaptable and capable of reflecting on their actions.
- The type 3 mode of educational work is an educational mode centred on social insertion. In effect, the trainers put the trainees in real conditions. The learners become *agents* in the sense of being able to act. They produce knowledge and anticipate what they have to learn at the same time as acting socially. The learners need a theoretical framework and tools to understand reality. Trainers and trainees share a democratic exercise of power. Sanctions come from reality, from the work. The principal agents of the educational mechanism are the trainers facilitating the relationship between the training and the circumstances of daily life. The learners, as agents, develop the capacity to modify the conditions in which their daily activities are exercised. They are capable of transforming reality.

This approach described by Lesne allows to anticipate the implementation of an educational process with an approach adapted to the targeted objectives. The question being: Should we create individuals who are capable of reproducing a practice (mental or physical) or of reflecting on their practice and transforming it in function to reality? These analyses on the choice of educational method to be used in relation to the social effects that they have on the learners are essential if we concentrate on

really achieving the objectives set by the sequences constructed during the production of action of therapeutic education.

Theoretical Foundations

TPE requires a mastery of the help relationship technique, using relevant educational tools with a view to responding to the variability of the mental processes of individuals and ensuring an educational support that is adapted to the particularities of each person. To do so, theoretical models from the social sciences and psychology can be used to support the educational techniques and represent effective practical supports to construct tools and processes that enable learning and personal development.

The NCI website refers to the CPEN who produced the guide: “establishing comprehensive cancer patient education programs: standards of practice”. This guide has compiled the international recommendations on therapeutic education since 1993. It references the theories that are useful in TPE and can be used by an educator to better understand the behaviour of individuals as well as that of populations.

	Theory/theory originator(s)/keywords
Individual health behaviour theories/models	Health belief model Source: Hochbaum, G Rosenstock, I & Kegals, S (1950) Perceived threat, perceived susceptibility, perceived severity, benefits and barriers to taking action, cues to action self-efficacy
	Cognitive dissonance theory Sources: Festinger, L (1957); Glanz, L & Rimer, B (1997) Cognition, conflict, consonance, dissonance, motivation
	Theory of reasoned action/planned behaviour Sources: Ajzen, I & Fishbein, M (1969, 1970, 1977, 1980); Behavioural intention, outcome expectancy, evaluation of likelihood of outcome expectancy, subjective norms, normative beliefs, motivation to comply, perceived behavioural control, control beliefs
	Protection motivation theory Sources: Rogers, R (1975); Threat appraisal, coping appraisal, severity vulnerability, self-efficacy, response efficacy
	Social cognitive theory Sources: Bandura, A & Walters, R (1963); Personal factors, behaviour, environmental factors, reciprocal determinism, triadic reciprocity between personal factors, modelling, vicarious learning, self-efficacy
Interpersonal health behaviour theories/models	Theory of interpersonal behaviour Sources: Triandis, H (1977, 1980, 1994, 1995) Cognitive, social, personal factors, habit, intentions, facilitating conditions Social support, control, stress and coping Sources: Caplan, G (1974); Cobb, S (1976); House, J (1981); Kahn, R & Antonucci, T (1980) Supportive behaviours, emotional support, appraisal support, informational support instrumental support, social capital

	Theory/theory originator(s)/keywords
	<p>Health locus of control theory Sources: Wallston, B, Wallston, K, Kaplan, G, Maides, S (1976) Expectancy, external locus of control, health externals, health internals, internal locus of control, powerful other, reinforcement</p> <p>Elaboration likelihood model Sources: Petty, R (1979) Cacioppo, J (1979) Persuasive communication, central route to persuasion, peripheral route to persuasion, motivation to process, ability to process, nature of cognitive processing, cognitive structure change, central positive attitude change, central negative attitude change, peripheral attitude shift peripheral cue present, attitude, boomerang attitude, persistence, resistance, behavioural prediction</p>
Stage theories/ models	<p>Piaget's child development theory Source: Piaget, J (1950s) Sensorimotor (birth, 2), preoperational (2–7), concrete operations (7–11), formal operations (11–15)</p> <p>Precede-proceed model Source: Green, L (1968–early 1980s) Precede: predisposing, reinforcing and enabling causes in education, diagnosis and evaluation Proceed: policy, regulatory and organizational constructs in education and environmental development Phases: social diagnosis, epidemiologic diagnosis, behaviour and environmental diagnosis education and organization diagnosis administrative and policy diagnosis implementation process: evaluation impact, evaluation outcome</p> <p>Transtheoretical model/stages of change theory Sources: Prochaska, J & DiClemente, C (1983) Stage, pre-contemplation, contemplation, preparation, action, maintenance Diffusion of health promotion innovation theory Source: Rogers, E (1962) Stages of Technological innovation knowledge persuasion decision, implementation, characteristics, relative advantage compatibility, complexity trialability observability, adopter categories, innovators early adopters, early majority, late majority, laggards, roles, opinion leaders, change agents, change aids</p> <p>Precaution adoption model Weinstein, N (1988) Work placements: unaware of issue, unengaged by issue, decided to act, decided not to act, decided to act, acting maintenance</p>
Social systems theory	<p>General systems theory von Bertalanffy, L (1950) Interrelatedness and interdependence of all phenomena, physical, biological, psychological, social, cultural</p> <p>Social marketing theory Sirgy, M (1984) The five “P’s”: product, price, place, promotion, positioning</p>

Example of a Programme: Anticancer Centre Paris

In France, to better understand life paths with cancer as a chronic disease, therapeutic education has been gaining ground in the last decade. The law pertaining to hospital reform and to patients, health and the territories of 21 July 2009 [10] requests that TPE programmes are offered to patients suffering from chronic disease, to ensure a better quality of life by reinforcing their skills but also to encourage compliance with the treatments and reduce readmittance to hospital. This involves the patients being supported by an educational caregiver to learn, make use of and incorporate new knowledge, know-how and clinical knowledge to help them stay alive.

Let us focus on a programme of therapeutic education developed 5 years ago in oncology, at the Institut Curie, Paris, France, to support patients taking oral anticancer drugs at home. The TACTIC programme was designed, created and implemented by a team of nurses. We will focus on the engineering modalities of the project to give an account of the procedural changes in terms of organization before describing the programme and its content, in order to understand the impacts for both patients and professionals.

Project Engineering

The implementation of an action of education requires the willing support of the institution, whatever the motivations (often financial or in the case of France the need for accreditation) and support for the logistical implementation (room, equipment, human resources, training). Prior work with the team on several levels was necessary for the implementation of this programme.

The educational provision occurs during a follow-up consultation for patients taking oral chemotherapy and was created at the initiative of the nurses in 2008. Initially it was decided to train a team of nurses and avoid allocating one single person to the project with a view to making this initiative durable. The team collectively decided to cease conducting the consultation in its previous form. Thus they decided to no longer give raw information but instead change the procedure to enable patients to use their existing knowledge and to obtain new knowledge. We decided to develop a TPE as an integral part of the care as opposed to a more categorized vision that positions education as an annex of the care. This decision required the instigation of training in therapeutic education (certified 40 h training) for the staff participating in the consultations. Participation in the training was on a volunteer basis so as to recruit nurses motivated by this project.

Within the department, regular meetings on the theme of TPE were held at a frequency of one per month to codevelop a common culture around this concept. The whole team was invited to these meetings to ensure that everyone understood and adhered to the values of this new practice, including those who would not be directly providing TPE. Indeed, it is vital to inform all the professionals in the team about the developments and transformations in their department so that they can support and encourage them and so that they recognize the legitimacy of the work

accomplished by their peers. To be able to accomplish all this, the doctor head of department and the head nurses supported and accompanied the project, the team and the initiatives which enabled the professionals to feel authorized to develop their practices in consolidating therapeutic education.

In order to develop the TPE, the nurses must change their position, integrate the active listening technique and consider the patients as capable. This paradigm at the level of the team upholds a new value: “it is the patient, even in his/her blindness, who is the guide, as s/he alone is able to indicate the path and give it meaning” [6]. This involves at times reassessing and working on oneself to be able to accept leaving aside one’s status of expert and to consider that the patient is producer of a work with an equal status to that of the health professionals. This change may be accomplished through regular coaching of the team members by the programme coordinator. She supports the process of her colleagues and enables them to integrate into the project and to find their place in it. She has a position of leader. The practice requires the nurses to change the paradigm, ascertain their position by integrating themselves into the project and give overall meaning to their actions.

By way of an exploratory phase, a group of patients met to experiment with a photo-language methodology with the aim of forming a focus group on their needs and expectations. Following this, another group of patients tested the programme in real conditions. Their proposals were used to change and readjust the sessions and workshops.

In summary, the ingredients necessary for execution of this TPE programme were the motivation and needs of the actors (professionals and patients), the durability of the project by the creation of a team, training, co-development of meaning, the leadership of a coordinator, institutional support and encouragement from superiors and regular coaching of the team members and of the team in its entirety.

The Programme

It is organized as follows: a shared educational assessment is conducted with the patient at the inclusion stage. “Bespoke” individual sessions and group workshops are offered with respect to the needs of each. The programme is not presented as such to the patient. For the nurses it constitutes a new approach to care provision which unconditionally includes education in the practice. In fact, with the patients the professionals do not use the terms “common educational assessment” or “educational workshops” which we consider as belonging to the hermetic language of the profession (behind the scenes, not necessary in the relationship with the patient). We think that these terms may induce a certain distance through distrust, recalling the rapport maintained in learning in childhood which may prove painful to some people. The use of these words may also distance people “from the heart of the relationship” by creating an overly conceptual rapport to the acts of support. In this way, the therapeutic education becomes an integral part of the care as a position that underpins the overlapping pedagogic and clinical biases.

During the shared educational assessment, the patients undertake an inventory with the caregiver on who they are, what they do, how they represent the disease, the treatments, their projects and how they live on a daily basis (activities, professions, organizations, etc.). This interview is conducted in the nursing consultation room with the patients when they leave the medical consultation with prescriptions of a new treatment to take. The nurse on duty receives the patients who are sent to her by the referring oncologists. At this point, a summary is co-produced with the person to identify the strengths and the weaknesses. The sessions and workshops which follow will be a response to these weaknesses. The sessions are based on the strengths and resources of the patients, enabling them to mobilize new clinical knowledge and work on their emotions, attitudes and feelings (Table 10.1).

Each patient chooses what she/he needs to know among the proposals made by the nurses. Overall the patients who benefit from this programme participate in

Table 10.1 TPE group workshops and individual sessions in the TACTIC programme

Individual sessions	Methods/tools	Skills developed
I know how to take the treatment	Prescription Box of medication Evocation of reality Annual schedule, a fluorescent pen, scissors	Become aware of the chronic nature of the disease, read, understand and interpret the prescription Take the treatment wisely, know the treatment Decide on the start date of administration, decide on where to store the box, divide the daily dose Plan intake over several months at home, swallow the treatment
I can read and interpret the CBC	Their latest complete blood count Fluorescent pen	Know the blood cells, know the function of the blood cells Know the signs of blood cell insufficiency Recognize the prodromes, physically act as a result Anticipate a critical situation, know the standards of the hospital Interpret the CBC with respect to these new norms, make a therapeutic decision Use wisely
I anticipate and I manage the potential side effects	DECLIC ACO game (maps and open questions)	Know the side effects Classify them according to their frequency of occurrence, know the normal clinical signs Recognize the pathological clinical signs, act in accordance with the appearance of these signs Take an appropriate treatment Adapt a treatment (doses, frequency), use wisely

(continued)

Table 10.1 (continued)

Individual sessions	Methods/tools	Skills developed
I can apply dressings alone	Dressing panel Scissors Drawings of cuts	Put the dressings on myself Identify the most suitable dressing depending on my everyday life and on the type of wound Seek help from a relative to explain the treatment Let myself be helped
I understand the physiology	Drawing Animated digital diagrams	Understand a physiological phenomenon, explain the physiological phenomenon
I prepare for the consultation with the doctor	Coaching Risk scale role play	Sound out my expectations of the consultations Prioritize my expectations Imagine the possible responses to each expectation, weigh the risk of each response Decide on the questions to ask, ask them

Group workshops	Methods/tools	Skills developed
I know how to eat when taking oral chemotherapy	FAQ Class of food table menus	Know which foods are compatible and incompatible with oral anticancer drugs Sort foods according to their class, identify my food needs Determine the benefits depending on the types of foods, know about food supplements Put together a menu and complement it if need be
I express my priorities	Short exercises (concepts)	Compare everyone's point of view
	Double optical illusions	Understand and integrate that we all have a unique vision of the world
	Role play	Identify our mechanisms of action regarding the difference of vision
	Real-life cases	Modify an inward-looking attitude, knows how to say <i>no</i> Express oneself humbly in reaction to the situation
I understand the disease and the treatments	Brainstorming Game of decision-making scale treatments, educational drawings	Share his/her representations of the disease and of the treatments Construct a process in a group around these representations Identify the impacts of the disease and of the treatments, understand each treatment Identify his/her place in the care pathway, decide to take his/her treatment Be motivated to act for oneself

four sessions or workshops. These people regularly return to the nursing consultation for a follow-up and can ask to address different themes depending on their needs at the time.

The Effects of the Programme

The assessment of the effects is subject to each person's subjectivity and singularity. Some of the teachings can be assessed in a tangible way, for example, in the case of the evidence-based clinical data to be learnt. However, it is much harder to accurately assess the development of behaviours and patient satisfaction. It could be interesting furthermore to develop an evaluative research protocol to document in a scientific way those effects.

The statements are often in verbatim form simply relating the patients' thoughts. Yet these statements are only discourses on the real and unreal, and there is at times a significant gap between the two. In any event, what we observe on a daily basis in the nursing consultations is that over time people no longer ask the same questions and those previously in the realm of the anxiety such as "the blood results are all in the red, what should I do? is it serious?" are progressively replaced by questions of a procedural and informative nature looking for validation from the professional, such as "my white globules are low, I stopped the chemotherapy". Thus, we observed that the practices change over time and interventions occur earlier and are more wisely judged.

We have also observed that it appears beneficial to have a non-formalized means of "leaving the programme" which seems to be linked to a degree of autonomy acquired by the person, until the appearance of a new need induces him/her come back. If this step is too formalized, this acquired autonomy may be damaged and therefore less beneficial for the individual. TPE is experienced as an opportunity by the patient.

The nurses like to run these workshops and sessions as they come out of them enriched and the co-construction in teams constitutes a meaningful creative investment for their profession.

Furthermore, we have noted that the doctors are often recruited to TPE by the patients. The change of position of the patients in relation to the oncologists provokes a change in their own positions.

In France, the educational actions in hospitals are organized in transversal units of education to promote an educational provision that follows the example of care provision. And the programmes produce very different mechanisms from one department to the next, creating microcultures [8]. This has an effect on the social roles expected of each individual.

Transformation of Social Roles

What the Development of TPE Changes for Professionals

New Modes of Organization of Care

Some nurses remain focused on technical care, while others become more specialized in support and education which are increasingly vast and complex fields open to increasing active channels. According to Pouteau, they “are looking for a new framework of exercise which enables them to mobilize their professional knowledge differently. They endeavour to maintain close links with the care departments, in order to keep up to date with technical developments and avoid giving rise to an overly pronounced differentiation in the roles” [9]. In fact, in the context of professionalization in TPE, it is necessary to support the change in the caregiver’s position towards the role and responsibility of an educator.

Towards New Skills

During the design and creation of workshops, the nurses develop and use educational games. Some of these games are suitable for dissemination on a large scale which requires precision and reliability in both form and content. The development of such games requires skills in logic, marketing, game design and legal aspects which broaden the field of action and impact of the professionals. Through these artefacts the nurses develop new skills. Their work is made visible, is formalized and provides them with a degree of recognition.

Gradual Changes in Tasks

When TPE is completely integrated in nursing care to the point where each contact with a patient is an opportunity to enable him/her to grow and to develop for him/herself, it takes nursing practice closer towards advanced practice.

The nurse carries out an individual education session: “interpreting and understanding blood tests (CBC)”. So, the patients may establish causal links between the values of the blood test and the intake or not of anticancer medications. They can then call to report that the CBC is too low and that they are suspending the intake of the anticancer drugs. Even telephone consent from the nurse to this decision serves as a validation for stopping the chemotherapy. This also applies to treatment resumption when the values of the complete blood count go back up and for a number of everyday procedures that would otherwise insidiously add to the daily workload of the nurses. Although these “task changes” in fact apply to procedures that should, legally, be performed by a professional and thus fall into the category of illegal practice of medicine, we also perceive that they are often a solution to the organizational constraints. “This phenomenon leads to the emergence of new professions

(nurse clinician, advanced practice nurse) based on organizing the work in teams permitting a controlled delegation of tasks and a redistribution of medical time to tasks with higher added value” [14]. A training in TPE and or in advanced practice at master’s level represents a means of advancing one’s career and decisively increasing the level of responsibility of the nurses, so they receive recognition in their new roles.

Difficulties Encountered in the Change of Role

The resulting questioning of professional territory may feed inter-professional conflicts or at times conflicts with oneself regarding the task that is self-prescribed. We also observe a reluctance to take the risk represented by this change of position or practice. This modifies the points of reference and habits of professional practice and takes the caregiver outside of his/her comfort zone, which is not acceptable for everyone. The analysis carried out by Dominice and Lasserre Moutet [3] shows that “training doctors in TPE” induces a “restructuring of medical thinking”. They talk about “sometimes difficult risk-taking” to “assume the status of marginality which can result from such a change of professional perspective” and of the “new representations of what learning means by becoming an educator”. According to Veilhan [19], the concept of patient researcher-actor in his/her health pathway may be intelligible, but it is difficult to integrate and appropriate into the core of the educational practice because of the fear of giving up the responsibility of the knowledgeable caregiver.

What the Development of TPE Changes for Patients

Empowerment

The government injunction in response to the increase in cancer patients – to do more with fewer resources – has resulted in a reduction of the time spent in hospital, and this obligation of efficacy requires profound transformations in care provision. An example from Gaspésie (Québec, Canada) is a large territory, a sparse population and a distant reference hospital. These factors have led to a policy to encourage patients to make tutorials on YouTube about common treatments (subcutaneous anticoagulants, etc.) and then circulate these videos by a shared network in connection with the health centres of Gaspésie. The patients involved then refer to this audiovisual resource addressing their concerns, with which they identify almost automatically (e.g., peer learning). The role of the nurses is thus modified; they eventually take on a coaching and supporting role when monitoring the patients who become the author and the actor of their lives. Thus the nurses abandon their role as the expert. This experiment shows that when you allow the patients to develop their potential to learn autonomously, they appropriate this world for themselves and transform it in accordance to their needs. According to Tourette Turgis, “the patients drive TPE forward and produce knowledge: putting the care subject in

a situation of knowledge production advances the care” [18]. “Any adult with experience carries unprecedented creativity and must be allowed to reveal this as an actor of change by permanent learning through research” [2]. Thus, being sick becomes in itself an object of research.

A Social Implication

The patients involved in the associations or having participated with the health professionals in the production of the programme or the workshops as a facilitator and creator occupy a position of social mediator and participate in the change of status of the patient. The patients move from being an object of interest to medicine to patients who actively think about their place and role and the relevance of their contributions and who are engaged through this pathology to politically represent their peers. This position-taking shifts the boundaries and leads to a step-by-step development of a true social role that undermines [12] definition of the status of the patient as one who cannot work and must obey the doctor. Here the patients become public players and transform society by “producing an asset in the collective and health field” [18]. Tourette Turgis adds that “recognition of the work of the patient becomes indispensable in the light of the chronicization of diseases. ‘This expertise of experience’ is necessary to improve the system of expertise of care”. In this respect we might think that tomorrow the work of the patient will be not only an object of research but also a job, even a profession, with a territory, a customer base, a language, etc.

Conclusion

TPE is a way of caring which, when well anchored in hospital services, can generate a common identity and, thereby, a common, even institutional, project, with benefits such as efficacy at work and a feeling of well-being.

During the implementation of an TPE programme or workshop or even an individual session, the overall vision of the nurses is essential as it reflects the educational foundations enabling learning: non-judgement, complex consideration of the individuals in their singularity, the subjectivity of their actions and choices and the unique causal links no longer pre-established by frames of reference that are not their own.

For Veilhan [19], “the passage from the position of caregiver to that of educator involves taking into account the experience of the patient as a subject possessing intelligence regarding his/her chronic pathology”. This means that the professional in oncology should agree to let go and overcome his/her ego. Human beings need to be allowed to change and evolve accompanied by recognition, valorization and the trust of others (patients, peers, superiors, other professionals). TPE enables everyone to learn from the outside world and about themselves. It is indispensable to be able to reorganize one’s daily life that has been irrevocably changed by the cancerous disease.

Changing this course of action requires an acceptance of the changes in the social role of the carers and patients. People suffering from cancer in the future may become professionals of their disease so as to add value to the work they accomplish daily to stay alive.

References

1. Cancer Patient Education Network (CPEN). Establishing comprehensive cancer patient education programs: standards of practice 24; 1998. Revised 2013.
2. Desroche H. Éducation permanente et utopie éducativerevue éducation permanente number 201. December 2014.
3. Dominice P, Lasserre Moutet A. pour une éducation thérapeutique porteuse de sens. Education permanente, édition n° 195-2013-2, apprendre du patient; 2013.
4. Gordon T, Sterling EW. Making the patient your partner: communication skills for doctors and other caregivers. Westport: Auburn House; 1997.
5. Lacroix A, Assal JP. L'éducation thérapeutique des patients, Accompagner les patients avec une maladie chronique: nouvelles approches, Collection Éducation du patient. 3rd ed. Paris: Maloine; 2011.
6. Lecorps P. education du patient: penser le patient comme « sujet » éduicable ? pédagogie médicale. 2004;5(2):82–6.
7. Lesne M. Travail pédagogique et formation d'adultes, éléments d'analyse. 2nd ed. Paris: l'harmattan (1st ed. 1977); 1994.
8. Liu M. Fondements et pratiques de la recherche-action, Collection Logiques So- ciales. Paris: L'Harmattan; 1997.
9. Llambrich C, Pouteau C. L'éducation thérapeutique du patient: du dire au faire, Une recherche-action qualitative associant six services hospitaliers français. Médecine des maladies Métaboliques. 2017;11(6):546–52.
10. Law n° 2009-879 of 21 July 2009 on hospital reform and patients, health and territories. JORF n°0167 of 22 July 2009, text n° 1. <https://www.legifrance.gouv.fr/eli/loi/2009/7/21/SASX0822640L/jo/texte>
11. Newman MA, Sime AM, Corcoran-Perry SA. The focus of the discipline of nursing. ANS Adv Nurs Sci. 1991;14:1–6.
12. Parsons T. The social system. Model Med Pract. 1951.
13. Pepin J, Ducharme F, Kérouc S. La pensée infirmière. 4th ed. Montréal: Chenelière Éducation; 2017.
14. Pouteau C. Expérience du geste intracorporel L'expérience des infirmières en interaction avec un malade dans le context d'un soin prescrit. Thesis, CNAM, Paris; 2018.
15. Rogers C. On becoming a person: a therapist's view of psychotherapy. London: Constable; 1977 (first published 1961).
16. Sandrin Berton B. et collectif. le patient au secours de la medecine, éducation et formation, biennale de l'éducation. Paris: PUF; 2000.
17. Strauss A, Fagerhaugh S, Suczek B, Wiener C. The work of hospitalized patients. Soc Sci Med. 1982.
18. Tourette Turgis C. quand l'évolution du champ de la santé rencontre celui de la formation... les défis de l'éducation thérapeutique du patient. jeudi de l'ARFREF, 20 November 2014.
19. Veilhan A. prise de risque: la formation ETP, une 'restructuration de la pensée médicale'. quand l'évolution du champ de la santé rencontre celui de la formation... les défis de l'éducation thérapeutique du patient. jeudi de l'ARFREF, 20 November 2014.
20. WHO. Therapeutic patient education: continuing education programmes for healthcare providers in the field of prevention of chronic diseases. Copenhagen: WHO Europe; 1998.