

Therapeutic patient education; A multifaceted approach to healthcare

ABSTRACT

This contribution presents a literature review of therapeutic patient education (TPE) in addition to providing a summary of an oral presentation given by two wound care specialists at a European Congress. It relates this to models of care in nursing science and to other research that contributes to this approach at the core of healthcare practice.

Keywords Therapeutic patient education, person-centred care, stomal therapy, wound care

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THERAPEUTIC PATIENT EDUCATION: AN INTRODUCTION TO ITS PRACTICAL APPLICATION IN PATIENTS WITH STOMAS AND/OR WOUNDS

Up until 1970, educational approaches were rare and limited to a few isolated interventions such as the 'manual for diabetics'. In 1972, Leona Miller, an American doctor, demonstrated the positive effects of patient education. Using a pedagogical approach, she enabled patients from under-resourced areas of Los Angeles living with diabetes to control their pathology and improve their independence by relying on less medication¹.

In 1975, Professor Jean Philippe Assal, a diabetologist from Geneva, Switzerland, adopted this concept and created a department for the treatment and education of diabetes at Geneva University Hospitals. He created an innovative, interdisciplinary team consisting of nurses, physicians, dieticians, psychologists, caregivers, art therapists and physiotherapists, all with the goal of encouraging patient engagement in their learning². The team was inspired by person-centred theories developed by Carl Rogers³, work by Kübler-Ross on the grief process⁴, contributions from Geneva on education science in adult learning, and work on

the conceptions of learners of didactics and epistemology of science in Geneva.

Since then, therapeutic education of patients (TPE) has been developed for patients with different chronic diseases and disorders, such as asthma, pulmonary insufficiency, cancer, inflammatory bowel disease and, in particular, for patients with stomas and/or wounds. The aim of TPE is to assist patients and caregivers to better understand the nature of the disease a person has, the treatment strategies required and to help patients achieve a greater level of individual autonomy in how they manage and cope with their disease.

DEFINITION OF THERAPEUTIC PATIENT EDUCATION (TPE)

According to the World Health Organization (1998), TPE is education managed by healthcare providers trained in the education of patients, and is designed to enable a patient (or a group of patients and families) to manage the treatment of their condition and prevent avoidable complications, while maintaining or improving quality of life. Its principal purpose is to produce a therapeutic effect additional to that of all other interventions – pharmacological, physical therapy, etc. Therapeutic patient education is designed therefore to train patients in the skills of self-managing or adapting treatment to their particular chronic disease, and in coping processes and skills. It should also contribute to reducing the cost of long-term care to patients and to society. It is essential to the efficient self-management and to the quality of care of all long-term diseases or conditions, although acutely ill patients should not be excluded from its benefits.

Thus, "TPE should enable patients to acquire and maintain abilities that allow them to optimally manage their lives with

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their disease. It is therefore a continuous process that should be integrated into healthcare”⁵.

The premise of TPE as a healthcare approach is that it places the patient(s) or the caregiver(s) at the centre of the healthcare provider patient relationship, acknowledging them as an integral partner in healthcare processes⁶⁻⁸. The cornerstone of this approach is that the patient has knowledge, skills and experiences that must be valued, encouraged, stimulated and/or explored. As for health practitioners, they need to recognise and highlight the patient’s knowledge about themselves and capabilities, which requires the health practitioner to adapt their own position to care provision and education. Healthcare providers often tend to talk to patients about their disease rather than train them in daily management processes to assist patients to better manage their condition⁵. As Gottlieb explains^{9,10}, it is more than a change in behaviour but a paradigmatic change that implores the practitioner to rely on the patient’s strengths rather than remedying their deficiencies and going further than Orem’s Model¹¹ proposed.

TPE is a model of education and support for people living with one or more chronic diseases. The goal is to support the person being cared for by engaging them with their care by means of an educational program which makes sense for them and, in doing so, reduces the risk of complications¹² and improves their quality of life. The tools of TPE promote a true collaboration between the patient and the healthcare practitioner. This requires a holistic, integrative and interdisciplinary approach¹³.

WHAT IS THE OBJECTIVE OF TPE? WHAT POSITION SHOULD PRACTITIONERS ADOPT?

The goal for practitioners who employ TPE is to enable their patients to become independent in their care processes and to improve their quality of life. Nevertheless, patient goals are not always the same at every juncture. For example, the sudden arrival of the disease, such as a colonic cancer and the formation of a stoma, which is often a consequence thereof, have a major impact on the patient’s life. The ostomy patient goes through many emotional processes that are often profound and intense which sometimes overwhelms them completely.

Therapeutic patient education aims to support the patient in the stages and process of this emotional adjustment so that they can better adapt¹⁴ to and accommodate their disease and stoma in their day-to-day life. The goal is for the patient to acquire skills for managing their stoma and treatment as well as psychosocial skills to integrate their stoma into their daily life.

The challenge for practitioners is to reconcile these two types of learning in the TPE program while taking into account the difficulties encountered by the patient and their learning needs. A therapeutic relationship based on mutual trust and partnership is an indispensable condition for this educational process. In the framework of this alliance, the emphasis is placed on a relationship of moral equivalence between the patient and practitioner¹⁵.

The first educational stage within the TPE framework constitutes encouraging and making space for the patient to express themselves in order to reveal and agree on their particular needs which may not always be evident to either the patient or the health practitioner.

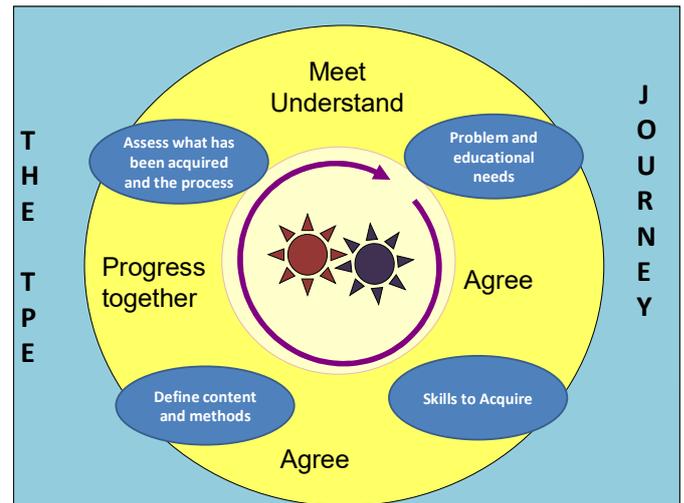


Figure 1. The TPE journey schema

In the TPE journey schema (the proposed Geneva TPE model), loosely translated from Lasserre Moutet et al.¹⁶ (Figure 1), the schema describes the following concepts:

1. The two cog wheels in the middle represent the patient and the practitioner, both engaged in active movement. They both possess a specific knowledge base of their own. The practitioner possesses scientific knowledge, clinical skills and their clinical experience with other patients who have faced similar healthcare conditions; the patient possesses their individual lived experience with their disease and their treatment in addition to their own knowledge. Although this relationship is, by nature, asymmetric, it is nevertheless not ranked in terms of knowledge. The practitioner is a mediator who supports the patient in the process of transforming their knowledge to better understand their disease, consequences of the disease process and remedial medical interventions. For these gears to work, the rhythm must be adjusted. The first part of the TPE journey is especially important in upholding this engagement: the patient and practitioner must agree on the problem, revealing the reality of the situations that the patient encounters on a daily basis. For the practitioner, this involves developing a genuine interest in the patient and their life story with their disease.
2. On the basis of this common understanding, educational needs, practical skills and competencies to be acquired by the patient will be elucidated in order for the patient to be able to overcome their difficulties or resolve their day-to-day problems.

3. Once the goals are defined in conjunction with the patient, the strategies employed will lead the patient to encounter new ideas, to experience a new perspective on their situation, and to find alternatives to organise their daily life.
4. Finally, the journey and the changes made will be evaluated jointly in order to make adjustments and continue the process.

This four-step approach can be carried out during one or more consultations.

WHAT KIND OF THERAPEUTIC EDUCATION SHOULD WE USE FOR PATIENTS WITH STOMAS?

Patients with stomas are confronted with physical changes and, often, a chronic disease^{17,18} which restricts their ability to envision a new reality for their life. One of the key roles of the stomal therapy nurse is to help the patient engage in suitable learning that will allow them to adapt, step by step, to a new life balance.

Whether the stoma is temporary or permanent, it is a shock and affects every aspect of the patient's life: social and professional life, emotional and family life, personal identity and self-esteem. In situations where the stoma is temporary, it is often seen as a major obstacle in the person's life for the period of time with which they live with the stoma. Once the intestine is reconnected, some patients dread that they will need a new stoma, which is indeed a possibility.

With the goal of patient independence with respect to the management of their care needs or, when this is not possible for the ostomy patient, for caregivers, stomal therapy nurses integrate TPE as a continuous process of comprehension of the patient's lived experience and create a partnership, teaching and informing the patient throughout all stages of treatment – pre-operative, postoperative, rehabilitation, home care and short- or long-term follow-up.

This patient's education focuses on different themes depending on the patient's needs. For example, organisational aspects related to the stoma (care, changing the appliance, balanced digestion, food safety, etc.) which necessitate self-care. Some self-adjustment difficulties, such as a distorted self-image, low self-esteem and additional psycho-emotional implications¹⁹⁻²¹ and difficulty talking about the disease or stoma with their social circle, or resuming sexual activity, will most likely require the development of psychosocial coping skills and competencies to facilitate adaptation. The practitioner can thus apply their knowledge, clinical know-how and interpersonal skills to find appropriate teaching strategies for the patient or caregiver's learning styles, all the while respecting/integrating patient's limits, fears, and any resistance in order to lead them through each step of the process. Ultimately, successful integration of these processes will allow patients to perform their own self-care and adapt to their life with the ostomy and sometimes their chronic disease.

WHAT STAGES DO OSTOMY PATIENTS GO THROUGH AND HOW CAN WE HELP THEM OVERCOME THEM?

According to Selder²², the lived experience of a chronic disease is akin to a journey through a disturbed reality that is full of uncertainty and which, ultimately, leads to a restructuring of that reality.

In order to mobilise the patient's resources, by working on their resilience^{23,24}, consilience (coping skills)²⁵ and empowerment²⁶ skills, practitioners must take it upon themselves to meet the person and understand their representations, values and beliefs^{27,28} in order to incorporate them into their healthcare. These aspects, which are very much linked to the socio-cultural and religious context that the individual has assimilated, must also be considered in order to integrate them into the care provided to them^{29,30}.

According to Bandura^{31,32}, patients' sense of self-efficacy relies on four aspects: personal mastery, modelling, social learning, and their physiological and emotional state. This generates three types of positive effects in patients with a good level of self-efficacy: the first relates to the choice of behaviours adopted, the second on the persistence of behaviours adopted, and the third on their great resilience in the face of unforeseen events and difficulties. Nurses who practise TPE will be able to mobilise, through their healthcare interventions, these four aspects of TPE for the purpose of inducing these three types of effects in the patient.

According to Diclemente et al.³³, behavioural life changes can only be carried out in stages. In stomal therapy, these patient-centred approaches begin in the pre-operative stage where explanations are provided to the patient (and family where possible) on the potential need for the stoma, the surgical procedure and postoperative care (WCET[®] recommendation 3.1.2, SOE=B+²⁹), even though the ostomy has not yet been confirmed. These recommendations have been adopted by the Wound Ostomy and Continence Nurses Society[®] (WOCN[®])³⁴.

The schema, adapted and loosely translated from Martin and Savary³⁵, describes the main steps of the learning process that need to be met and nurtured (Figure 2). Depending on the age of the patient, the knowledge, tools, and processes employed in adult education, TPE requirements may be necessary components to mobilise in order to attain them^{36,37}. Other strategies will need to be adopted for younger populations, particularly with respect to adolescents^{38,39}.

EXAMPLES OF PROBLEMS AND GOALS IN THE THERAPEUTIC EDUCATION OF PATIENTS WITH STOMAS

These problems and instructional goals may apply for patients with incontinent ostomies, which are reflective of the most encountered scenarios (Table 1).

In the case of patients with other, less common types of ostomy, like those with continent ostomies or nutritional support ostomies^{40,41}, some of these items are still applicable and/or will need to be adapted to their particular situation;

Table 1

| Problems | Learning goals |
|---|---|
| Patients with stomas feel restricted in leading the lives they would like because they are unable to control the evacuation of urine (urostomy) or stool and gas (jejunostomy, ileostomy or colostomy), undergoing the undesirable effects of nutrition on digestive transit. | <ul style="list-style-type: none"> Identify their emotions and ideas related to the restrictions that the ostomy represents. Explain new sensations and reactions of the digestive system using their day-to-day experiences. Adapt their diet to control the evacuation of urine and/or stool and gas. Plan and allocate food intake taking into account their activities. Define strategies to control new sensations: the production of gas and noises. |
| Ostomy patients may consider not leaving the house out of fear that the pouch will be visible under their clothing or leak. | <ul style="list-style-type: none"> Share their fears with their social circle and with caregivers. Clarify the aspects of their clothing to change in order for them to feel at ease and comfortable while maintaining a sense of fashion that appeals to them. Choose their strategies and experiment with them. Identify 'coaches' in their social circle to help them modify their wardrobe (organise a 'fashion show' etc.). Become aware of their strengths, learn to value them, and discover new ones. |
| Patients with stomas feel overwhelmed and do not feel capable of caring for their stoma and changing the appliance. | <ul style="list-style-type: none"> Locate their resources, strengths, abilities. Identify what is important for them and what is worth continuing to fight for. |
| Ileostomy patients, or those with a high-flow stoma, may force themselves to stop eating or drinking in order to limit the flow of liquid stool. | <ul style="list-style-type: none"> Understand the deleterious effects of this behaviour on their health. Know the signs of dehydration. Learn means of hydration and food that can solidify the stool and/or acidify their urine. Identify the physical signs and interpret them as manifestations of dehydration. Implement, to the best of their ability, recommendations regarding hydration and diet to prevent dehydration. |
| Ostomy patients have difficulty confronting their image of themselves. | <ul style="list-style-type: none"> 'Make peace' with their body image. Identify the different aspects of their suffering with respect to their altered body image. Identify situations in daily life where they feel embarrassed and those where they feel OK. Identify aspects of their physical appearance that they particularly appreciate. Review their criteria for positive self-image. Adopt practical means for living more comfortably with their new image (clothing, new pouch or accessories, etc.) in different contexts of their life. |

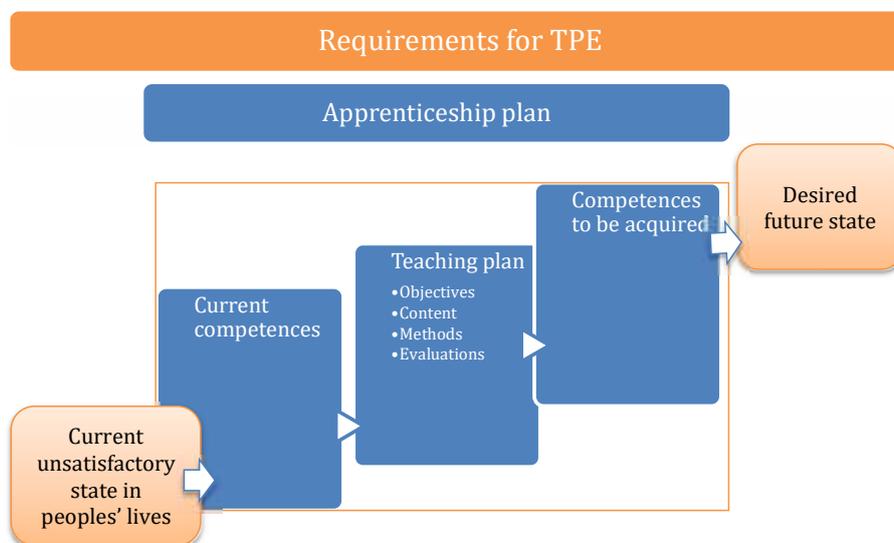


Figure 2. TPE requirements

additional and more specific problems may apply. This is also the case for patients with enterocutaneous fistulae⁴².

In some situations, whether due to disgust, refusal, denial and/or disability (motor function, cerebral, psycho-emotional or psychiatric), the ostomy patient may not be able to undergo some or all of these processes of learning and empowerment⁴³. This can be a short-term, medium-term or sometimes long-term problem. In these instances, recourse to a caregiver, whether a practitioner or a close relative, should be envisaged and organised. The educational process necessary for their empowerment must be carried out in a relatively similar manner with a view on promoting patient enabling to the maximum extent possible that allows the ostomy patient to return home. To the latter must be added supportive communication and management of and potential changes to interpersonal relationships and, potentially, to intimate relationships between the patients and their partners. Such changes can be generated by applying the principles of TPE, and this type of care and will need to be regularly re-evaluated and taken into consideration with a holistic approach to the patient and their respective situations.

These processes are even more complicated for patients who live alone at home, and even more so if they are elderly, as this can call their discharge home into question as well as their ability to remain at home. The need for strong communication relays and networks to be implemented in these circumstances recalls the advice offered within the 2012 American Association of Retired Persons (AARP) report^{45,46}.

Lastly, the ostomy patient will occasionally find themselves with more than one stoma, all of which may be permanent (Figures 3 and 4). From our experience, these complex situations are more frequent than they were previously and are often related to malignant pathology.



Figure 3. Example of a person with a permanent left colostomy and a trans-ileal cutaneous ureterostomy (Bricker's intervention) with purple urine bag syndrome⁴⁷.

INSIGHTS AND FURTHER INFORMATION RELATING TO PATIENTS WITH CHRONIC WOUNDS

Contrary to some preconceptions, stomal therapy is not solely concerned with the care of ostomy patients, even though the usage of the original term enterostomal therapist (ET)⁴⁸ may



Figure 4. Example of a postoperative patient several days later with a temporary colostomy and a protective ileostomy. Digestive continuity would be restored in 9 months over two interventions, commencing with the downstream ostomy before the upstream ostomy, over an interval of a few weeks.

lead to confusion. Indeed, the full Enterostomal Therapist Nursing Education Program (ETNEP)⁴⁹ includes providing healthcare for people with wounds, people with continence disorders, those with enterocutaneous fistulae and, in some schools, for those with mastectomies. That said, wound care specialisation has become a specialist service unto itself and many ETs or stomal therapy nurses collaborate closely with wound specialists. It is important to note that these aspects of patient education are specified in the European curriculum for nurses specialising in wound care (Units 3 & 4)⁵⁰⁻⁵².

In the literature, in reference to education provided to patients with wounds, knowledge has been described as a process of self-management, particularly among individuals living with a chronic disease such as a leg ulcer⁵³. For education to be effective, the patient must acquire a perceived benefit from the changes that their involvement in the preventive activities proposed could generate. Physical, or emotional, benefits will reinforce the positive effects of the advice given⁵⁴.

The benefit of using a multimedia teaching approach lies in the combination of methods for transmitting information. This helps resolve the problems encountered by the patient but also reinforces the information they are provided with^{55,56}.

Numerous Cochrane Systematic Reviews have been carried out regarding patients with venous ulcers, diabetic foot ulcers and pressure injuries. They have revealed that:

- For patients with leg ulcers, there is not enough research available to assess strategies for supporting patients that would increase their adherence /compliance, despite the fact that compliance with compression is recognised as an important factor in preventing leg ulcer recurrence⁵⁷.
- In relation to diabetic patients, there is not enough evidence to say that education – in the absence of other preventive measures – is sufficient to reduce the occurrence of foot lesions and foot/lower limb amputations⁵⁸.

- Finally, as for pressure injuries, the authors have noted that the idea of patient involvement remains vague and includes a significant number of factors which vary and include a wide range of interventions and possible activities. At the same time, they clarify that this involvement in care, such as the respect of the rights of the patient, are important values which could play a role in their healthcare. This involvement could have the benefit of improving their motivation and knowledge in relation to their health. In addition, such involvement could entail an increase in their ability to manage their disease and to take care of themselves, thus improving their sense of security and enabling them to have better results when it comes to improving their health⁵⁹.

As for patients with cancerous wounds, the European Oncology Nursing Society recommendations note the existence of scales for the evaluation of symptoms for the typology of these wounds, allowing for early detection of associated complications, as well as the reduction of care-related costs and of equipment used in healthcare, all the while improving patient involvement. Indeed, some of the tools described could be suggested to patients for them to use to assist with managing their condition⁶⁰. In order for this to happen, education on their use will be necessary, despite the fact that these people may have lost confidence in themselves, their treatment, and their healthcare teams; even though their disease may have improved, their wounds still serve as visible stigmas of their disease.

Conclusion

Therapeutic education is the cornerstone of interventions conducted with individuals with chronic disease, or in chronic conditions, with the goal of health-related promotion, prevention and education. It is a fundamental activity that cuts across all the fields of the specialisation in stomal therapy. As every situation is unique, therapeutic education enables practitioners to develop skills in this area to improve the provision of care. It also incites us to innovate, be creative, adapt, and to think outside the box in order to find other interventional strategies; it also requires us to show humility, which may lead us to ask for help via our professional networks nationally and/or internationally.

According to Adams⁶¹, TPE remains a vast area of interventions in which the utility of educational interventions in improving healthcare impacts are still under discussion. However, the results of studies are still too limited to support their evidence. For other authors, the efficacy has, to date, been borne out by the research. For many hospitals, it is reportedly a cost-saving measure, as it enables shorter hospital stays and reduces the number of complications⁶²⁻⁶⁶.

Lastly, while the educational process starts at the hospital, it is followed up in both outpatient and home care services. In this sense, the implementation and maintenance of communication relays will be primordial in ensuring continuity of care, coherence and coordination of the processes

undertaken as well as those of future stages that will be collaboratively decided upon. The involvement of family caregivers in these processes, with the consent of the patient and their relatives, is important. They serve as resources that cannot be neglected, even though their involvement may generate other issues that must be accounted for.

The training of healthcare professionals, particularly nurses, in the application of TPE will reinforce their expertise and efficiency⁶⁷ in patient education, with the knowledge that every situation will push them to find new strategies and skills to overcome the challenges faced.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

The wound section was partially based on notes taken during the University Conference Model (UCM) session⁶⁸ on the subject. This session took place at the 2017 Congress of the European Wound Management Association (EWMA) in Amsterdam, Netherlands, and was presented by Julie Jordan O'Brien, Clinical Nurse Specialist Tissue Viability and Véronique Urbaniak, Advanced Practice Nurse⁶⁹.

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