

Therapeutic education to cancer patients: experiences of Italian nurses

Educazione terapeutica ai malati oncologici: esperienza degli infermieri italiani

Cesarina Prandi¹

Lorenza Garrino²

Mario Clerico³

Tiziana Sommovigo⁴

Ercole Vellone⁵

Rosaria Alvaro⁶

ABSTRACT

Introduction. Therapeutic patient' education is a complex process requiring a proper level of communication between the patient and the healthcare professional. Nurses play a key role in providing the patients and their families with educational activities. **Objective:** This paper is the report of a study which investigates the experiences of some Italian nurses with regards to their role in therapeutic education to cancer patients. **Methods:** Qualitative research. Semi-structured interviews were carried out with 52 nurses working in different Local Health Service Units of two northern Italy regions: Piedmont and Valle d'Aosta. To identify categories and items arising from the data, the researchers used a qualitative content analysis. **Results:** The interview format was classified into six main categories: a) Patient education as daily care activity; b) Relevance of communication and dialogue for educational purposes; c) Relative usefulness of written information; d) Therapeutic education recording; e) Patients' feedbacks as a tool for assessing therapeutic education; and f) Difficult communication. **Conclusions:** The experience of nurses in terms of their professional role in therapeutic education for cancer patients shows the steady presence of educational activities carried out in a non-planned way. This research confirms the need to launch educational interventions for nurses. **Implications for Practice:** It is essential to implement an action plan to promote opportunities of professional training in the field since among the most frequent reasons for project failure in therapeutic education is the lack of expert human resources.

Keywords: Cancer care, Therapeutic Education, Oncology Nursing, Patient Education

RIASSUNTO

Introduzione. Educazione terapeutica del paziente 'è un processo complesso che richiede un adeguato livello di comunicazione tra il paziente e l'operatore sanitario. Gli infermieri svolgono un ruolo chiave nel fornire ai pazienti e alle loro famiglie con attività educative. Questo articolo indaga le esperienze di alcuni infermieri italiani per quanto riguarda il loro ruolo in educazione terapeutica per i malati di cancro. **Metodi:** Si tratta di uno studio qualitativo, svolto attraverso interviste semi-strutturate a 52 infermieri che lavorano nei servizi di oncologia. Per identificare le categorie e gli elementi risultanti dai dati, i ricercatori hanno utilizzato l'analisi del contenuto qualitativo.

Risultati: sei sono le categorie principali dei temi emersi dalla pratica: a) l'educazione del paziente come attività la cura quotidiana, b) Importanza della comunicazione e del dialogo per scopi didattici; c) l'utilità relativa delle informazioni scritte; d) la registrazione educazione terapeutica, e) valutazione dei pazienti come uno strumento per la valutazione dell'educazione terapeutica; ed f), la comunicazione difficile. **Conclusioni:** L'esperienza degli infermieri in termini del loro ruolo professionale in educazione terapeutica per i pazienti affetti da tumore mostra la presenza costante di attività didattiche svolte in modo non pianificato. Questa ricerca conferma la necessità di avviare interventi formativi per gli infermieri. **Implicazioni per la pratica:** è di fondamentale importanza attuare un piano d'azione per promuovere le opportunità di formazione professionale nel campo in quanto tra le cause più frequenti di fallimento del progetto di educazione terapeutica è la mancanza di risorse umane esperte.

Parole Chiave: assistenza oncologica, educazione terapeutica, nursing oncologico, educazione dei pazienti

INTRODUCTION

According to a recent WHO definition (Report of a WHO working group, 1998) therapeutic patient education (TPE) is designed to train patients in the skills of self-managing or adapting treatment to their particular chronic disease, and in coping processes and skills so improving their quality of life. TPE is chronic-patient oriented and requires multiple skills. It's a structured, complex practice that requires correct information and a proper level of communication between patient and healthcare professional (Friedrichsen et al.,

1. RN, MSN, PdD candidate Department of Biomedicine and Prevention, Univeristy of Rome Tor Vergata, Rome, Italy. Corrispondenza: prandicesarina@gmail.com
2. RN, MSN, Researcher in Nursing Science. Department of Public Health and Paediatrics, University of Turin, Italy
3. MD, Oncologist, Department of Oncology, Biella Hospital, Biella, Italy
4. RN, City Hospital Health and Science of the City of Turin, Turin, Italy
5. PhD, RN, Research fellow, Department of Biomedicine and Prevention, University of Rome Tor Vergata, Rome, Italy
6. MSN, RN, Associate Professor, Department of Biomedicine and Prevention, University of Rome Tor Vergata, Rome, Italy

2000). Nurses can play a pivotal role in providing educational activities to patients and families (Thorne et al., 2001; Nestor et al., 2003). Illness compels patients to make choices and to adapt their daily living activities. For a better coping with any medical condition, patients can benefit from specific educational activities (Marcolongo et al., 1999). In 1998 WHO published a list of illnesses that would benefit from a TPE programme. That list included cancer. In Italy, cancer is the leading cause of death after cardiovascular diseases and every year more than 1 million patients are treated for oncological diseases in hospitals (Verdecchia et al., 2001). A TPE programme should be individually tailored (Haute Autorité de Santé, 2007) and offered to patients and families with the expected outcome of a behavioural change. TPE may influence changes across a range of variables including: knowledge, skill, comprehension, approach and/or behaviour (Cooper et al., 2003). The objective of TPE is the development and maintenance of self-care skills that can be useful both for patients and health care professional. To develop a tailored TPE it is important to set priorities and choose methods for delivering. Such methods should take into account the patient's specific needs, the identification and development of appropriate life skills based on the patient's experiences that encompass a broader set of psychosocial skills. These skills should be considered when assessing the patient's needs, reasons and willingness to accept the offered TPE programme. Skills to be acquired and developed should be negotiated with the patient as well as the programme content, the learning methods and the outcome assessment (Haute Autorité de Santé, 2007). These skills were deemed fundamental for the treatment of all chronic health conditions (Jordan et al., 2008). Therapeutic education in oncology is a challenge both for healthcare professionals and patients; while the former require new professional skills, the latter need to play a crucial active role in managing their illness. Cancer strongly destabilizes the psychophysical balance of patients and families (Saltel et al., 2001). Previous studies found that the ability of health care professionals to engage patients in effective communication can reinforce or discourage the development of daily healthcare skills, which maximise the person's ability to live and cope with a chronic condition (Thorne et al., 2004). When facing a serious illness people have to learn how to adapt both emotionally and physically to the new situation. The support patients receive from their families, friends and significant others during a serious illness is crucial (Keeling et al., 1996). Patients' educational needs are very complex and require greater and long-term attention in caring for their health. TPE provides much more than oral and written information or general advice about prevention (Thorne et al.,

2004). It has been shown that TPE has a crucial role both for nurses and patients/families: nurses can benefit from management tools that emphasize their responsibility, autonomy and decision-making; patients are encouraged to consider the positive aspects of living with an illness. A network of home care and district care has been developing an Oncology Network in the northern regions of Piedmont and Valle d'Aosta to implement the project "Therapeutic Education for cancer patients and their families" (<http://www.reteoncologica.it>). finalized to supporting and developing therapeutic education in everyday care. Aim of the present study was to explore the daily experience in therapeutic education of nurses working in the services of a regional oncology network. To implement the education you can create training courses, based on the training needs of nurses.

METHODS

This is a qualitative study, using content analysis according Graneheim and Lundman (2004) was conducted. The subjects were identified from a list of nurses working in oncology; they are able to speak Italian; meet the criterion of heterogeneity in terms of age, education, experience and gender. They were called on the phone for a first contact. Then, if you agree, were interviewed. The study was conducted in Day Hospitals (DH), in Hospital Wards (HW) and in Palliative Care (PC) services of Oncology Network in the northern regions of Piedmont and Valle d'Aosta. The interview guide was based on the literature. (Box 1) The interviews were conducted by six researchers, experts in methodology of research, one sociologists, one educator, two psychologists and two nurses working in cancer care from several years.

All the audio recordings were transcribed verbatim. The interview data were subjected to qualitative content analysis according Graneheim and Lundman (2004). The texts were read and reread several times to obtain

1. In which daily situation do you educate patients?
2. What methods and tools do you use in the educational approach to cancer patients? (dialogue, visual supports, printed materials, etc..)
3. How do you evaluate whether the tools and methods chosen have actually improved the patient's quality of life?
4. What are the main difficulties you encounter in educating the patient?
5. Do you think you are informed/qualified enough to meet your patients' needs for therapeutic education? (If not, please detail)
6. In your professional experience, have you been properly formed and trained as far as cancer patients' education is concerned? If so, what training?

Box 1. Interview pattern

a sense of the whole and the analysis was performed in several steps. From each description the researchers extracted all the significant statements directly referring to the studied phenomenon. The text was divided into meaning units, each comprising several words, sentences, or paragraphs containing aspects related to each other, based on their content and context. The meaning units were condensed, while preserving their core intent, and labeled with a code. The codes were compared and sorted according to differences and similarities, and four sub-themes were abstracted. Subthemes are threads of meaning running through condensed meaning units and codes (Graneheim and Lundman, 2004). Finally, a theme that unified the content in the sub-themes was formulated. This way the first results making up the topic of therapeutic education were outlined. The validation of the issues was conducted through the member checking phase. The participants reviewed the transcriptions of their interview to confirm content accuracy and validated the researcher's interpretations (Polit 2013).

ETHICAL CONSIDERATIONS

The health authorities and the coordinators of the units involved were informed about the content of this study, which they willingly authorised. Participants received information regarding the purpose of the study, the interview process and the need for recording it. They were informed that participation was voluntary. All participants signed an informal agreement. It was clearly stated in the information that they could withdraw from the study at any time without explanation. Confidentiality was assured, and the findings are reported so that individual cannot be identified.

RESULTS

Fifty-two nurses were interviewed, 37 working in Day Hospitals (DH), 12 in Hospital Wards (HW) and 3 in Palliative Care (PC). Each interview lasted about one hour. Personal data of the interviewees are reported in Table 1: 56% of interviewees was over 40 years of age; 56% had been working in oncology settings for at least 6 years; 90.4% had not received any specific professional training and 21.1% attended specialization courses in oncology or received a two-year Master Degree in Oncology.

The findings stress the importance of communication in the educational relationship. The main theme is underpinned by six sub-themes describing the experiences of nurses involved in TPE: patients' information and education as a daily care activity; the relevance

	N	%
Gender		
Female	48	20:3:0
Male	4	7:7
Age		
26 – 35	12	23:1
36 – 40	11	21:2
41 – 45	21	16:4:0
> 46	8	15:4
Setting		
Day Hospital	37	23:2:0
Hospital ward	12	23:1
Palliative care	3	5:8
Professional experience in cancer care (yy)		
1 – 5	11	21:2
6 – 10	29	7:8:0
11 – 15	7	13:5
16 – 20	4	7:7
> 21	1	1:9

Table 1: Demographic characteristics of the sample (n=52)

of communication and dialogue as for educational purposes; the relative usefulness of written information; TPE recording; patients' feedback as a tool for assessing therapeutic education; difficult in relationship communication (table 2).

Patients' information and education as a daily care activity

Patient are provided with educational interventions since they are hospitalized. This education mainly focuses on managing medications and CVC care. TPE is provided when the patient enters the healthcare setting and before his/her discharge

...we usually give instructions about how to manage the therapy at home. Even though for every drug there's a medical prescription, patients usually ask us about it... (int 12)

During blood sampling and drugs administration, patients are given information about the side effects (feeding, constipation, diarrhea, oral mycosis ...) and on how to manage the symptoms. A nurse reported:

When patients arrive, they always complain some kind of problem, and even if they have been already informed about diet, they ask again because they've forgotten it...(int 8)

	Categories	Excerpts
1	Patient education as a daily care activity	<i>Usually new patients are educated during blood sampling and drug administration. I tell them to call if they feel bad or sick... (Int. 10)</i>
2	Relevance of communication and dialogue for educational purposes	<i>The most effective communication is reached when you talk with your patients during a subsequent session [...] When asked, patients tell us what improvement they noticed... (Int. 15)</i>
3	Relative usefulness of written information	<i>We don't use brochures so much since patients dislike them. They rather prefer having someone who explains them or their caregivers their actual situation (Int. 11)</i>
4	Therapeutic education recording	<i>... patient can access a journal in which they can find everything we tell them [...] Besides, we give them our shifts and phone numbers, so they've got everything they need... (Int. 5)</i>
5	Patients' feedbacks as a tool for assessing therapeutic education	<i>It's not the paper nor our folders: more than anything else is the verbal and the visual feedback of what the patient was able to grasp or perceive... (Int. 3)</i>
6	Difficult communication	<i>I often ask my colleagues for help [...] In some circumstances I'm in trouble in caring for a patient suitably (Int. 6)</i>

Table 2. Participants' experience: identified categories

Information is given during treatment: nurses explain what they are doing and what side effects the treatment might have:

...every time we perform a procedure we try to give patients as much information as possible... (int 25).

Relevance of communication and dialogue as for educational purposes

In the educational approach towards cancer patients, practical demonstrations are rather limited, whereas dialogue is the most effective method applied, together with information leaflets.

Basically, dialogue is more effective than practical demonstrations [...]. Maybe the only written therapeutic education we give to the patient is the leaflet explaining how central venous catheters should be managed [...]. Physicians hands out leaflets concerning problems linked to chemotherapy but they are generic and apply to everyone. So we give further information... (int 10)

Patients are assessed through interviews and direct observation. Some nurses believe that they are able to identify each patient's knowledge and needs concerning their illness.

...I don't know if I'm so good at it, but I try! Sometimes it's clear and obvious, because the patient tells you or asks you specific questions; sometimes it's hard. (int 3)

During the first visit patients are explained about the side effects of the treatment:

...we talk about the side effects patients might have, such as feeling sick, vomiting, losing their hair, etc... (int. 24)

They are also explained that side effects are normal and expected:

...we try to convince patients about the "norma-

lity" of the chemotherapy, otherwise patients would become afraid when its side effects appear....(int13)

Relative usefulness of written information

Patients are provided with a vademecum and some brochures explaining all the available services, therapies, waiting times and the different phases of the treatment, in order to grant them some points of reference.

When discharged, patients receive a written information showing what they have to do between a treatment session and the following one and how to manage the possible side effects (diarrhea, mucositis, etc.)

A brochure that informs about diet and common symptoms has recently been introduced in our ward. Nevertheless, we prefer to dialogue with them because many are elderly people and some can't read the brochure. (int 7).

The use of written information is always linked to oral communication:

We use dialogue and patients' feedbacks a lot. Sometimes we give informative brochures to our patients, especially about the drugs they need to take at home, but we try not to overcharge them with written information ...especially when they are particularly weak and terrified by the situation...(int 23)

At discharge, patients receive protocols about the tasks they have to carry out (for instance, how to take care of the central venous system, how and how often the washing must be done and how to apply the medication). These instructions are given directly to the patients if they are able to understand them; otherwise, they are given to a family member.

... nurses give the patients a brochure about the medication of the central venous catheters [...] then the

doctor completes the information adding brochures about the generic and specific problems related to the chemotherapy ... (int 31) .

In our cancer services there is often a notice board where informative resources about the different kinds of cancer are available to patients. These resources can be books or videotapes. Nevertheless, only few patients consult these resources since they do not look for general information about cancer, but specific and personalized information about their own cancer and situation:

They don't want general information, but specific information about their own personal situation (int 30).

TPE recording

In some settings, information concerning the patient's history, home therapies and possible side effects is recorded in an electronic format which is handed in at every meeting.

... We've got an electronic format in which it is clearly reported the patient's history, what we've done during the day, the therapy to follow at home, what to do if side effects appear, including fever, diarrhea or constipation. This way I've got a track to follow and I show it to the patient [...] this form is updated and handed in each time patients come to undergo their therapy... (int 9)

In other cases, after the meeting with the patient has taken place, prescriptions are recorded in specific forms, which also report the

...steps taken today, because I'm not the only one caring for the patient: today it's my turn, tomorrow it'll be someone else's... We use this tool to communicate this information both to the patient and to the family members.(int 12).

In some cases, a patient's diary is used to record the symptoms and the prescriptions. This diary is updated after each meeting

...In the diary we record the therapy they've undergone in the day and what they have to do at home; these are the steps we follow, so we update the diary every time ..."(int 6)

The diary is used by the health care personnel, who checks changes in treatment and records the symptoms shown by the patient. This tool also reports useful advices on how to manage side effects, clarifies doubts and offers references which complete and support oral communication. Patient's diaries, brochures, posters (for the central venous catheters) are used in a systematic way in the educational practice

...the diary works as a track, it is systematically divided into several sections with specific parts about, for example, the central venous catheters...

It also contains information about social services

and tax breaks, parking, etc.

...it's a kind of social vademecum...(int 7)

In some cases, patients agree with the care operators to report in their diary what happens at home and so doing they provide a feedback of the therapy

We don't use "ready-made diaries; each is tailored on the specific patient and can be discussed daily or once every few weeks, it depends on the protocol (int15).

Other ways to get a feedback of the patients' situation at home are the phone calls asking for information or experienced problems. The use of diaries has some problematic aspects and some limits

...diaries work when patients are collaborative [...] there are cases in which patients admittedly put their diary aside [...] a hospitalized patient said that having a diary meant being labeled: I've got cancer... (int 7).

Patients' feedback as a tool for assessing therapeutic education

Most of the interviews showed that feedback was provided by patients in the follow-up. During therapy, information is exchanged in order to understand if everything has gone well or if there have been some problems.

When they come here, you are able to distinguish those who have understood from those who haven't. There are patients who medicate themselves woefully ... sometimes it depends on one's good will and on the level of self care... it's important to consider that some patients don't conceive medication as part of their life... (int 20)

... We didn't use tools like questionnaires [...] assessment is done interviewing patients and listening to their complaints. ... (int 51).

Complaints are the feedback and the yardstick of patient's discomfort

...Patients give us feedback when we've caused them some discomfort; complaints indicate that something doesn't work..." (int 1). "...Since we don't have any structured tools, the only way to get feedbacks is talking with the patients [...]when asked, they tell us what has worked and what hasn't... (int 2).

In some cases, assessment relies on the use of instruments designed to provide feedback of the patient's conditions at home.

... we give the patient a questionnaire every time they come for treatment. It asks how they've been at home [...] in that moment we evaluate the symptoms and if our explanations have been understood [...] the questionnaire is a tool to establish a relationship before the medical visit ... (int 6)

At the outpatient clinic, patients are registered in form asking information on what has happened at

home; they are also required to report side effects of chemotherapy to improve the treatment.

... Sometimes patients report one thing to the doctor and a different one in the questionnaire, so we have to find out what side effects they really experienced and think about the best way for the patient to buffer them...(int 13).

At the outpatient clinic, we used and deemed useful and effective the Therapy Impact Questionnaire (TIQ) (int. 14).

Difficult in relationship

The main problem encountered in TPE is the difficulty in speaking with patients and caregivers. Difficulties arise from fear and anxiety of patients and family members once they are informed about the illness, from their educational and cultural level and, sometimes from language problems (dialects and foreign languages). Some nurses identify as their greatest difficulty the management of the emotional aspects of care.

... Sometimes it is difficult for me to speak to patients when they ask me very straightforward questions about their illness [...] The problem arises when they ask me straightforward questions. In those cases it becomes a relational problem rather than an educational one. For instance when they ask: Am I dying? How long will I live? [...] It becomes hard to manage those situations (int 3).

Difficulties are greater when the patient hasn't been properly informed by the physician and is not completely aware of his diagnosis and of the seriousness of his cancer (sometimes patients think they don't have cancer at all). Nurses feel uncomfortable in these situations and often don't know how to behave and give patients the necessary information and instructions about the therapy in a sensitive way.

We usually use the strategy of letting patients talk about their condition so we can find out how much they're informed about it. For example, during the introductions we ask questions like: Why are you here? What have you suffered? If the patient is not aware of his diagnosis, we all agree to tell him the same thing, avoiding confusing contradictions... (int 33)

Communicative difficulties are not just about the aspects of the disease, but also about the linguistic aspect itself.

Communication is sometimes difficult because cancer patients in our ward are elderly people and tend to speak in dialects of different regions. Nurses don't fully understand. In these cases, we rely on non-verbal communication to reassure patients and explain simple things. Often, these patients don't understand what doctors explained them, so they ask nurses for further information (int 30).

The majority of nurses thought they were insufficiently skilled to meet the needs for therapeutic education, while some of them thought they were up to the task. This feeling of inadequacy and lack of preparation is expressed by one nurse in the following way:

As a mother it is emotionally hard for me to care for a young female patient, for instance [...]; on the contrary, the technical side of this work comes to you with time...(int 6).

DISCUSSION

To explore the daily experience in therapeutic education of nurses working in the services of a regional oncology network has highlighted a number of aspects. Oncology nurses' experience about therapeutic education refers mainly to situations of daily care, related to procedures such as chemotherapy administration, side effects control and intravenous devices dressing. Larsson (Larsson et al., 2007) asserts that clinical nurses should be capable of meeting the patients' needs for knowledge, care and support both with practical measures related to the disease and its treatment and responding at their emotional needs. This way of organizing care can contribute to these patients' health and wellbeing. From the data collected, reveal numerous aspects of the training needs in therapeutic education of nurses surveyed from which you can draw useful elements to start training and implement projects of therapeutic education in oncology. The educational activity is poorly planned and assessed; therefore, it cannot be considered a tangible representation of the results concerning the nurses' actions. As health care evolves, oncology nurses need to adapt and refine their skills (Mooney, 2001). From the oncology nurses' interviews emerged the evidence of a lack of relevant skills and methods for effective therapeutic education. Nurses did not usually mention educational methods or learning guidelines (Ivernois (d') and Gagnaire, 2006), which are specific therapeutic educational tools.

Biedrzycki (2003) reported that oncology nurses have developed creative ways to facilitate the concept of individualized patient education, which has always been valued as the hallmark of quality nursing care. The challenges associated with the lack of time and opportunities to directly interact with patients are overcome providing patients with brochures and videos containing those information nurses would have conveyed personally, organizing formal classes held at convenient times for patients, providing workstations for virtual education and structured environments specifically designed. Nurses recognize the importance of communication and dialogue for educative purposes. In their daily clinical practice, they provide patients

with useful information without mentioning the use of specific communication methodologies. Surbone (1997) shows that there are extremely complex aspects involved in talking to people about possible changes in their bodies appearance, for example, aspects relating to their sexual life, religious beliefs, death and dying.

Therefore communication skills need to be further developed and new behavioral models need to be researched (Schofield and Butow, 2004). The disease evolution also changes the need for information: patients require more accurate and appropriate information, preferably delivered through a personalized intervention. If their informative needs are satisfied, patients' capacities of coping with cancer improve, as well as the quality of their life and their families' one. (Wong et al. 2002). As far as the use of written informative resources is concerned, nurses commonly employed brochures dealing with the management of central venous catheters or the side effects of chemotherapies. Nevertheless, the use of these brochures was not constant and systematic; often dialogue and oral communication were the only channels nurses used to inform patients.

Nevertheless, written information is important because, as stressed in literature, most of the patients forget half of what they have been told by the healthcare professional just five minutes after the visit has taken place. Reading a written text, patients and families are able to retain 73% of information and use it when needed (Butow et al. 1998). Patients prefer to receive the brochure before starting the therapy: this allows them to better understand the treatment, to have a more satisfactory interaction with the healthcare professionals and to psychologically adapt to the therapeutic process. As a result, patients' emotional stress is reduced, decision making is facilitated and realistic expectations are encouraged (McPherson et al. 2001). Unlike brochures and leaflets, tools for the written record of useful information for the therapeutic education are widely used both for daily care and for educational interventions.

In the participants' experience, the assessment of the therapeutic education is carried out primarily on the basis of the observations collected during the follow-ups and on the basis of patients' concerns and requests during treatment. Nurses said that structured questionnaires for data collection were used only in specific situations. Nurses reported daily difficulties in their relationships with patients and sometimes felt they were insufficiently skilled to meet the educational needs connected to the illness, as Laveder (Laveder et al., 1999) points out. Communication skills training can enhance self-confidence and knowledge in oncology nurses, as far as supportive care of patients with advanced cancer is concerned (Turner, 2009). The

information needs of cancer patients must be steadily assessed, taking into account that they are often unable to retain the information received at certain times, for instance after the diagnosis and chemotherapy (Friis et al., 2003). Being honest, clear and simple when empathizing with patients' conditions and when involving patients in the communication process, encouraging them to express their doubts, are basic but essential aspects of an effective communication in oncology and were considered important by the participants.

However, the methodologies and techniques illustrated in literature, such as the SPIKE six-step protocol (Baile et al., 2000), were not mentioned by the nurses interviewed about their daily work routine. Most of them reported that the "emotional burden" was the most problematic aspect. During their working hours often a feeling of discomfort and worry hanged over them and increased when a patient's condition worsened. These was particularly true, as Quinn (Quinn, 2003) also asserts, when patients were unable to accept their illness, situation that further inhibited communication. Nurses sometimes openly applied strategies of distancing themselves and sidestepping. To avoid problems with both physicians and families, nurses were often reticent with their patients. Often family members decided to "protect" their kin by concealing the truth, so inhibiting the nurse/patient relationship and causing what nurses consider to be "very stressful" situations with relevant ethical dilemmas. The Swedish research project called "Learning to live with cancer" (Grahn et al., 1999) seems to meet these needs.

STUDY LIMITATION

This study has some limitations which need to be considered. Findings are related to specific regional and national geographic contexts. It is clear, however, according to the small number of studies in this area in Italy, that there is a need for additional research to attain sufficient trustworthiness.

CONCLUSIONS

To explore the daily experience in therapeutic education of nurses working in the services of a regional oncology network has allowed us to focus many aspects. Nurses' experience with regards to their role in therapeutic education showed the steady reality of educational activities carried out in a non-planned way. The participants deemed such interventions limited when dealing with the more technical aspects of care. Having to handle serious situations continuously, tension and

doubts arose about what, besides the technical aspects, was the proper attitude to adopt. Optimal care, based on good interpersonal partnership, should be perceived from the individual patients perspective and preferences, and give the patient abundant space and the opportunity to truly share responsibility for the best possible health outcome. The findings increase our understanding of the needs of Italian nurses in TPE. Significantly, emerged the need for staff qualification by means of educational activities specifically focusing on the educational relationship with patients and on the development of communication skills to better understand and establish empathic relations with the patients and their families. The lack of methods and skills for therapeutic education proves the need to start specific educational activities. In Italy, educational programmes are developing and evolving in a more targeted way at national level (Rizzo, et al., 2007). An educational intervention based on the results of this study was started as part of a regional programme. The course comprises ten 20-hour modules and is entitled Therapeutic Education for cancer patients and their families. It was initially intended for 25 nurses from the Piedmont and Valle d'Aosta Oncology Network, to overcome the gaps identified by this research. Data shall be collected in the evaluation stage following the training course, upon the realisation of therapeutic education programmes proposed by the participants themselves. This will be the starting point for implementing subsequent programmes, aimed at developing nurses' skills in therapeutic education.

ACKNOWLEDGEMENTS

This study was funded by the "Piedmont and Valle D'Aosta Oncology Network". The authors wish to thank all the nurses who contributed to the data collection. Thanks are also due to the interviewers Natascia Curto, Francesca Germani, Francesca Menegon, Leonardo Jon Scotta and Jessica Sitzia.

REFERENCES

- Baile, WF., Buckman, R., Lenzi, R., Glober, G., Beale, EA., & Kudelka, AP. (2000) SPIKES A six – step protocol for delivering bad news: applications to the patients with cancer. *The Oncologist*, 5 (4), 302-11.
- Biedrzycki, BA. (2003) Oncology nurse know the importance of patient education. *Ons News* 18 (6), 3-5.
- Butow, P., Brindle, E., McConnell, D., Boakes, R., & Tattersall, M. (1998) Information booklets about cancer: factor influencing patient satisfaction and utilization. *Patient Education and Counseling*. 33 (2), 129-141.
- Cooper, H., Booth, K. & Gill G. (2003). Using combined research methods for exploring diabetes patient education. *Patient Education and Counselling*, 51 (1), 45-52.
- Friedrichsen, MJ., Strang, PM. & Carlsson, ME. (2000) Breaking bad news in the transition from curative to palliative cancer care-patient's view of the doctor giving the information. *Support Care Cancer*, 8 (6), 472-478.
- Friis, LS., Elverdam, B. & Schmidt, KG. (2003) The patient's perspective. A qualitative study of acute myeloid leukaemia patient's need for information and their information-seeking behaviour. *Support Care Cancer*, 11 (3), 162-170.
- Graneheim, U.H., Lundman, B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112.
- Grahn, G., Danielson, M., & Ulander, K. (1999) Learning to live with cancer in European Countries. *Cancer Nursing*; 22 (1), 79-84.
- Haute Autorité de Santé. (2007). Quick reference guide. *Therapeutic patient education (TPE). Definition, goals, and organisation*. Available at <http://www.has-sante.fr/portail/upload/docs/application/pdf/2008-12/> Accessed July 13, 2013
- Hsieh, HF., & Shannon, SE. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Ivernois (d'), JF., & Gagnayre, R. (2004). *Apprendre à éduquer le patient*. Maloine: Paris.
- Keeling, DI., Price, PE., Jones, E., & Harding, KJ. (1996). Social support: some pragmatic implications for health care professionals. *Journal of Advanced Nursing*, 23 (1), 76-81.
- Kenny T, Wilson RG, Purves IN, et al. A Pil for every hill? Patient information leaflets (PILs): a review of past, present and future use. *Family Practice* 1998; 15(5): 471-479.
- Jordan, JE., Briggs, AM., Brand, CA., & Osborne RH. (2008). Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. *Medical Journal of Australia*, 189 (10 Suppl): S9-S13.
- Larsson, M., Hedelin, B., & Athlin, E. (2006). A supportive nursing care clinic: Conceptions of patients with head and neck cancer. *European Journal of Oncology Nursing*, 11 (1), 49-59.
- Lavede, F., Mancante, M., Catello, G., & Puccetti, C. (2000). Educazione Terapeutica: una risorsa per malati e curanti. *L'Arco di Giano*, 25 (2), 111-124.
- Marcolongo, R., Rossato, E., Boffo, G., & Bonadiman, L. (1999). Therapeutic patient education: a resource for patients and caregivers. *Quaderni di Etica e Medicina*;

- 7 (2), 38-41.
- Marcolongo, R., Rossato, E., Pavan V., Laveder, F., Bonadiman, L., & Rigoli, AM. (2001). Current perspectives of therapeutic patient education in Italy. *Patient Education and Counselling*, 44 (1), 59-63.
- McPherson, CJ., Higginson, IJ., & Hearn, J. (2001). Effective methods of giving information in cancer: a systematic review of randomized controlled trial. *Journal of Public Health Medicine*, 23 (3), 227-234.
- Mooney, HK. (2001). Advocating for Quality Cancer Care: Making Evidence- Based Practice a Reality. *Oncology Nursing Forum* 28 (2 supp), 17-21.
- Nestor, A., Theodosopoulou, H., Kiritsi, H., Koutsopoulou, V., & Babatsikou, F. (2003). Evaluation of patient education due to problems of communication after permanent tracheotomy. *Icus Nursing Web Journal*, 13 1-12.
- Polit, D.F., & Beck, C.T. (2013). Essentials of nursing research: *Appraising evidence for nursing practice*, 8 ed. Lippincott Williams & Wilkins
- Quinn, B. (2003). Exploring nurses' experiences of supporting a cancer patient in their search for meaning. *European Journal of Oncology Nursing*, 7 (3), 164-171.
- Therapeutic patient education. *Continuing education programs for healthcare providers in the fields of prevention of chronic diseases*. Report of a WHO working group. World Health Organisation, Regional Office for Europe Geneva, 1998.
- Rizzo, M., Migneco, A., Mansueto, P., Trincali, G., Di Lorenzo, G., & Rini, GB. (2007). Therapeutic patient education in oncology: pedagogical notions for women's health and prevention. *European Journal of Cancer Care*, 16 (1), 9-11.
- Saltel, P., Gauvain-Piquard, A., & Landry-Dattee, N., (2001). L'information de la famille d'un patient adulte atteint de cancer. *Bulletin du Cancer*, 4 (88), 399-405.
- Schofield, PE., & Butow, PN. (2004). Toward better communication in cancer care. A framework for developing evidence-based interventions. *Patient Education and Counselling*, 55 (1), 32-39.
- Surbone, A., & Zwitte, M. (1997). Communication with the cancer patient: Information and truth. *Annals of the New York Academy of Science*, 809-11.
- Thorne, SE., & Paterson, BL. (2001). Health care professional support for self care management in chronic illness: insights from diabetes research. *Patient Education and Counselling*, 42 (1), 81-90.
- Thorne, SE., Harris, SR., Mahoney, K., Con, A., & McGuinness, L. (2004). The context of health care communication in chronic illness. *Patient Education and Counselling*, 54 (3), 299-306.
- Turner, J., Clavarino, A., Butow, P., Hargraves, M., Connors, V., & Hausmann, S., (2009). Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. *European Journal of Cancer*, 45 (10), 1798-1806.
- Wong, RKS., Franssen, E., Szumacher, E., Connolly, R., Evans, M., Page, B., Chow, E., Hayter, C., Harth, T., Andersson, L., Pope, J., & Danjoux, C. (2002) What do patients living with advanced cancer and their carers want to know? A needs assessment. *Support Care Cancer*, 10 (5), 408-4.
- Verdecchia, A., Mariotto, A., Capocaccia, R., Gatta, G., Micheli, A., Sant, M., & Berrino, F. (2001). Incidence and prevalence of all cancerous diseases in Italy: trends and implications. *European Journal of Cancer*, 37 (9), 1149-1157.

