Master of Public Health

Master international de Santé Publique

Contribution to a program of therapeutic education of patient (TPE) involving patients treated for cancer with special concern at Educational Diagnosis, for the recognition of best method and time for educational diagnosis of hospitalized cancer patients on chemotherapy.

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Student: Shamim Akhter QURESHI
MBBS
Email: shamimtanveer@gmail.com
Class: M2 Class
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Practicum Location: Teaching Hospital (CHU) Rouen, France

Professional advisors [CHU, Rouen]: Professor Dr. CZERNICHOW Pierre
Academic advisor [EHESP]: Professor Dr ZMIROU Denis
Reporters: Professor D.Bard, Professor B.Parent

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List of Abbreviations

ARS *Agence régionale de santé* (Regional access for health department of France)

CHU University Hospital (Teaching Hospital)

ED Educational Diagnosis

HAS *Haute Autorité de Santé:* (High health authority department of France*)*

INCa Institute for cancer research (French)

RCPs *Réunion des Concertations Pluri-disciplinaires (*Multidisciplinary meetings)

TPE Therapeutic Patient Education

WHO World Health Organization

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ABSTRACT

Back Ground:

Over the course of the last century, the focus of medicine has largely switched from acute diseases to chronic diseases. In addition to 'technical' medical therapy, patients who live with chronic conditions generally require long-term follow-up, and continuity of care. Most chronic diseases tend to have a progressive element and treatment often comprises both curative and preventative elements. Therapeutic Patient Education (TPE) is recognized as one of the best tools to prevent complications and to improve patients' quality of life. There are well-developed programs already existing for diabetes and asthma and now for hospitalized cancer patients, a new program is in progress at the Teaching Hospital of Rouen, France. The therapeutic education team is working closely with the actors of the medico-psycho-social personnel for this new program. Four steps are established for TPE. The first one is Educational Diagnosis, which is the basic element to construct an educational programme for an individual patient and this is the focus of this paper.

Objective:

To identify the best time and method to conduct educational diagnosis for hospitalized cancer patients on chemotherapy.

Methods**:**

The process of care for cancer patients was observed at a French Teaching Hospital using patient medical records chronologically from the first day of their contact with the hospital. The patient-doctor consultations to announce cancer diagnosis, daily routine hospital meetings and multi-disciplinary meetings (RCPs) were attended. Personal interviews of patients and professionals were also conducted to investigate the best timing and method for ED.

Hospital personnel training sessions in TPE are already in progress and some were observed as part of this study. Project meetings of the professionals and hospital staff to construct the TPE program were also observed.

Results:

All patients and professional agreed that personal interviews are the best method for educational diagnosis and that these interviews should to start ED should not be too soon after the announcement consultation because of patient stress. For timing, the patients were uncertain but amongst the eleven professionals, eight agreed that the ED should be finalized after the weekly meeting.

Conclusion:

There is reasonable consensus that the personal interviews where patients meet individually the medical personnel, are the best method of making educational diagnosis, and is

preferred by the patient over completing questionnaires. The ED is a multi-disciplinary decision that would then take place at the next weekly meeting. However, the ED is constantly reviewed during the patient journey and could evolve depending on changing situations.

KEY WORDS: Announcement consultation, nurse consultation, educational diagnosis, Therapeutic Patient Education, *classeur* (medical work books to be filled by the patients)

INTRODUCTION

Progress in medicine and changes in our society have led to an increasing number of patients with chronic diseases. On the other hand the doctor- patient relationship has been changing. These two factors have lead to the concept of TPE. In the past, a hierarchical, imbalanced and disproportionate relationship between doctor and patient was usual; the patient was only supposed to ask for a consultation paper from his doctor, to buy his drugs, and was not supposed to have any knowledge or skill about his own disease. Even in recent past the patient had no right to access directly to his own medical record, only a doctor could do it. Nowadays the situation of patients has dramatically changed. In 2004[1] a law concerning rights for patients was introduced in France according to which the patients have to be informed by their doctors, and were allowed to have direct access to their personal record and also a possibility to choose their treatment, making them equal partners for the management of their disease[2].

TPE is understood as a coordinated set of educational activities, proposed by health professionals or a health care team, involving other professionals and also patient representatives (members of patient groups, patient resources) to people living with chronic illness and their families. The ultimate aim is usually to enable individuals to make appropriate and informed personal choices to manage their condition in their daily lives. This approach is commonly referred to as '*patient empowerment*'. The more traditional objectives of patient education have been considered to be based on behaviour change or improved adherence to a given treatment plan. Although these may contribute to improved clinical outcome, more patient-centred outcome measures, such as patient satisfaction, emotional wellbeing and quality of life have to be promoted. Just providing oral or written information or advice about prevention is not considered as TPE[2]. Even today, most of the time care is disease-oriented rather than patient-oriented. According to WHO, "the therapeutic patient education designed to help patients gain or maintain the skills they need to best manage their lives with a chronic illness. It is a part permanently to the care of the patient. It includes organized activities, including psychosocial support, designed to make patients aware and informed of their disease, care, organization and hospital procedures, and behaviours related to health and disease. This aims to help them (and their families)

understand their illness and treatment, work together and assume their responsibilities in their own care in order to help maintain and improve their quality of life[3]. "

Specifically, the therapeutic patient education is part of a treatment plan, it is multi professional and can be offered at different times of patient monitoring.

The HAS has already establish a guide for this, including four basic steps:

1- To make an educational diagnosis
2- To Establish a tailored TPE programme with learning priorities
3- To provide group or individual sessions (or both)
4- To Assess acquired skills and to revise programme if necessary[2]

OBJECTIVES

This project was undertaken during a Master of Public Health (MPH) internship at the Epidemiology Department of the Teaching Hospital Rouen, France. This practicum was a part of MPH 2 curriculum of the French School of Public Health (EHESP).

In Teaching Hospital Rouen, a new program of TPE is under elaboration for the cancer patients. The contribution was done about educational diagnosis.

This paper contains two parts

1-the literature review

2- the practical part of observation

This paper has two main objectives. The first one is to identify the best method for the educational needs of the cancer patients (Educational Diagnosis).

The second objective is to identify the best timing to do this during the whole care process of cancer patient. At the same time special focus is made on TPE for cancer patients in an overall view and to observe how to elaborate a new program in medical world. This also helped to observe the functioning of a hospital in a developed country.

To achieve these objectives a literature review was done. A qualitative study was also performed. Based on patients and professional's interviews and by observing the whole process of care of cancer patient, the observation aimed to address two basic questions related to the ED.

The paper is structured as follows. First, the method and materials used are described. A primary data collection was necessary by conducting interviews. The questionnaires for the interviews were structured. Hence, the analysis of the questionnaires is synthesized in the result section. Finally, the discussion section draws the main lessons.

Cancer management in host institution

According to a study conducted in Teaching Hospital Rouen, during the year 2009, it is reported that 4903 patients were admitted at least for once with a cancerous disease in

Teaching Hospital Rouen. These patients spent 72175 days of hospitalisation and 18120 stays at Teaching, mean stays were 3, 7 and on average 14,7 days per patient for the study period. The mean age of the patients admitted at the CHU is 63.2 years. (Data is taken from the Hospital informatics).

METHODOLOGY

1- Literature review

The knowledge got from literature review helped to clear the concepts about TPE, ED and also the need for the elaboration of a TPE program for cancer patients. Secondly it helped to decide how to get qualitative data.

2 -*Observational parts*

a) This part of work was an observation for ten days in two different cancer departments of the hospital. The whole process of care of cancer patients was observed, the medical staff was followed to see how do they work with cancer patients and at what time it would be possible to make an educational diagnosis.

- The care process is observed. This includes the routine collection of information from patients and medical staff in a hospital,
- Cancer diagnosis announcements and educational consultations were attended; (each time the verbal consent was taken from the patient for author's presence during the consultation),
- All the routine meetings in a cancer department were observed,
- Attending multidisciplinary meetings (RCPs),
- Analysis of the personal medical records of the cancer patients and also of *Classeur* (see page no.20) to have an idea of the dates of each event of their follow-ups. The verbal permission was obtained from the departmental heads to have an access to the medical records and the informatics' information was received from the chief nurses from their computers.

b) The method also consisted of collecting primary data by leading interviews of cancer patients and professionals. This primary data collection was necessary as the literature review highlighted a lack of qualitative study on educational diagnosis.
Semi structured Interviews of hospitalised cancer patients and professionals involved in care were conducted. No note- book or audio- tape was used during the patient interview to give a very relaxed environment to respond. It was like a very friendly conversation. For

professionals, the notebook was used during the interview. The purpose of the interview was explained well before the interview, to both groups. All patients and some professional were also explained about ED before asking the questions. After the interviews of professionals, the answers were noted immediately on the note- book in the office not to forget them after. Each patient was with different kind of education, sex, age, profession, and co-morbidities. Different professionals of medical line were interviewed like four Doctors, two Nurses, one Psychologist, one Psychiatrist two nursing chiefs and one coordinating nurse.
The data collected was not for the comparison of groups.

Two questionnaires were formed, one for patients and other for professionals with open and closed ended questions. The questionnaires were structured after the observation of the whole process of care in the cancer wards. The interviews data were gathered in Excel in order to analyze the most common answers. The detail of the questions and their answers is given in the annexes (tables 1,2,3a, 3b.).

To contribute to TPE program the care process was chronologically analyzed to describe the timing and relationships between events that have occurred during the management of the patient, what happened to the patient from the day 1st and who intervened at what time. It helped to find out which method was best to have educational diagnoses and at what time it would be better to do educational diagnosis, and at the same time to have an idea of the best timing for diagnostic announcements and educational consultations by analyzing of whole process of care.

Knowledge from literature review

In a recent French law[1], the influence of TPE as a factor of quality and proximity care was underlined. Until 1 January 2011 TPE programs have to be submitted for approval to the new *Agence régionale de santé* (ARS). These programs will be evaluated by the *Haute Autorité de santé.* Article 84 also seeks to structure the actions that accompany the patient and supervise the apprenticeship programs, two areas contributing to the TPE who fall outside these specifications. Regionally, the conditions of approval and renewal of a program by the ARS are defined by Decree No. XXX XX. Decree of XXX n° XX is to develop a programme. We need authorisation and funding from ARS[4].

A pool of 320 scientific papers on TPE was screened to select controlled experiments in chronic disease where the dependent variables included (a) compliance with therapeutic regimen, (b) physiological progress of patients or (c) long-range outcome[5]. Thirty such papers were found; and the magnitude of effects of TPE was estimated through a meta-analysis. TPE was proved to be the most successful in altering compliance (average improvement over control = 0.67 sigma, $p < 0.05$). However, average improvements were found both in physiological progress (0.49 sigma, $p < 0.01$) and health outcome (0.02 sigma,

$p < 0.05$). Efforts to improve health status by increasing patient knowledge alone were rarely successful. Patient's behaviour-oriented programs that also include changed environment were consistently more successful to improve the clinical course of chronic disease.

TPE has also led to a significant decrease in the number of hospital admissions for patients with asthma or diabetes. In those patients, both a decrease of lower limb amputations and more generally a better quality of life was associated with TPE[6].

TPE in cancer management

Cancer is becoming a leading cause of death worldwide. According to the World Health Organization (WHO), cancer was the cause for 7.4 million deaths in the world (around 13% of all deaths) in 2004[7]. However, more than 30% of cancer deaths could be prevented with better screening strategies, diet, or environment for some cancer and complications can be reduced by the involvement of patients in their therapies[8].

The TPE was only recently introduced in cancer after its recognition as a chronic disease. . The lengthening survival time of cancer patients, which contributes to making cancer a chronic disease, as well as changes in the patient-caregiver relationship contribute to the development of therapeutic education in cancer. TPE is complementary to the healthcare approach and aims to get the patients more involved in their disease and the treatment decision-making process. It can also contribute to reducing the cost of long-term care to patients and to society though it should not be considered the main objective of this program. This discipline, placed at the interface of human and social sciences was first developed for the management of chronic diseases (diabetes, asthma). In oncology, the contribution of therapeutic education may enable the patients to have adequate information of the illness, to actively participate in the management of the disease, to understand how to live with cancer, to learn how to face the critical moments of long clinical course, and to live in harmony with all health professionals involved in cancer treatment. In addition, there may be several advantages for health professionals: a reduction in emotional labour, increased professional satisfaction, and a reduction in the potential tensions and conflicts with patients and their relatives[9].

Need for the elaboration of TPE programs

Patient's rights are now defined in several countries by laws after the pressure of social associations for the management of cancer patients. Like in France, the "League against Cancer" association played a very active role to promote the quality of announcement of the

cancer diagnosis. They insisted that its quality not only depends on the relationship that develops between patient and physician but also the coordination of all the professionals who surround the patient at that time. The announcement device implemented in France under the Cancer Plan is based on the time of consultation and coordination, treatment time, nursing support time, coordination with the family doctor and access to supportive care. National recommendations for the implementation of the device are being propose[10].
Pilot studies, conducted principally in the United States, evaluating the side effects of chemotherapy and the management of pain, have demonstrated that such educational programs could improve patient quality of life and decrease the side effects of treatments[9]. The success of these programs depends on several parameters: taking into account patient's opinion in the elaboration and preparation of the programs; involving skilled multidisciplinary teams engaged in iterative educational actions and having recourse to methodological tools to evaluate the impact of implemented programs. Consistent with WHO guidelines, research has been conducted in France in order to elaborate and implement cancer-specific education programs and evaluate their potential benefit. Patient education programs on pain, fatigue, nutrition and treatment compliance are currently being developed in different regions of France.

In France, the Second Cancer Plan 2009-2013 is presented on the report submitted to the President of Republic by Professor Jean-Pierre Grünfeld in February 2009. The new plan is a continuation of the Cancer Plan 2003-2007 and will take a better consideration and strengthening the coordination of care and its extension beyond the hospital through greater involvement of physicians. New initiatives are proposed involving medico-social workers to better assist people in "life during and after cancer. The plan also customizes the care of patients and strengthens the role of the physician and will always involve the physician. This personalized program will take into account the individual needs of medical supervision, psychological support and social assistance during and after cancer[11]. Cancer plans recommend100% responsibility of a cancer-patient. This involves all his medical, social, psychological and legal matters, so all-individual aspects of a cancer patient are recommended to take into responsibility. The complexity of cancer care and the many parties involved require better coordination to improve patient support during and after the acute stage of their treatment. Strengthening a coordinated multidisciplinary approach, largely based on new communication tools, is one guarantee of quality of care. Patients need a Well-organised coordinated care involving many intermediaries. These intermediaries may be general practitioners, nurses in private practice, pharmacists or regional, multidisciplinary health networks[3].

According to the Second Cancer Plane, the Measure 19 "improves the quality of care for all cancer patients". To achieve this goal an announcement procedure and the use of expanded multidisciplinary treatment planning meetings are recognised as measures that have improved the quality of cancer care. To receive 100% of new cancer patients in a multidisciplinary consultation about their case, the term "personalized program of care" is synthesized.

Another recommendation (19.5) states" provide patients and their families with reference information guides based on the good practice guidelines, designed for specialists and developed according to HAS (Higher Health Authority) and INCa methodologies, so that they can play an active role in the care system. These measures and also the other measures like personal care plan, access to supportive care must take effect by the end of 2011 after getting proper authorisation according to the cancer plans[12].

National Cancer League demanded for patients and their families to provide them with up-to-date and comprehensive reference information on medical, social, legal and practical issues concerning different forms of cancer[10].

The concept of TPE is already present in different forms in the medical world as an individual initiative without any specific training but not to the professional level. It depends on individual personality of different medical personals if they want to do it, they do and sometimes if some others don't want, they don't do it at all; it's not an obligation. Now we need to present a structured programme so that everyone can follow and do it on the same pattern for a specific chronic disease as different diseases require different programs and on some points the same thing (individually tailored or adopted as each patient is unique and requires different kind of education). It is not possible to involve one patient in different programs even he has got co morbidities. Our team is trying to make a structured framework to implement a customized program for health professionals, social associations, patients and their families (all beneficiaries).

TPE programming has been neglected. Its methodology has never been adequately formalized and this creates difficulties in educating other health care providers. Treatment of long-term diseases is less satisfactory than it might be. Quality of care still depends considerably on skills of patients and other forms of medical technology. Although health care providers in general and physicians in particular are competent in diagnosis and selection of medication, they have in general been taught neither the skills of therapeutic patient education nor methods of efficient long-term care. The proposed programmes would fill this need. They should be part of the life-long learning of health care providers and could also be included in basic professional education and in the education of specialists in long-term care. Health care providers trained in those educational skills may contribute to: improved quality of life, as well as longer life, of their long-term care patients; improved

quality of care in general (as acutely ill patients should also benefit from those educational skills).

To have the expected outcome of care for patients and for the quality of the educational process, care providers and educational specialists need to perform periodic evaluation against defined criteria. The educational principles of proposed programmes and their local Implementation include Programmes of recognized quality should serve as models that health centres could gradually adopt in their own time and by their own means. Such model programmes will need to be adapted to local circumstances and constraints provided the adaptations do not contradict the basic principle.

A TPE programme must be individually tailored. The medical personnel should have the skills to analyse the patient's needs, motivation, and willingness to accept the TPE programme on offer, and when negotiating with the patient the skills to be acquired and maintained, programme content, learning methods, and assessment of outcomes.

Over the last decade in the WHO European Region, the health professions have been under some pressure to promote patient education as a major addition to pharmacological, physical and other forms of therapy. Nevertheless, health care providers still need urgent and efficient educational programmes in the long-term management of chronic diseases. Current programmes do not usually include educational methods or psychological support of patients. Their methodology has never been adequately formalized and this creates difficulties in educating other health care providers. Bibliographical review has shown that less than 5% of articles on patient education describe the educational process and the methods used[13].

Educational Diagnosis

Educational diagnosis is the first step of the educational process. It is a systematic, comprehensive, iterative collection of information by the health care provider concerning the patient's bio clinical, educational, psychological and social status. This information is to serve as a basis for the construction of an individualized TPE. To set the targets for each patient, program of TPE should include a time of "educational diagnosis" or "shared educational record" leading to the definition of goals tailored to each patient. An educational diagnosis is made individually for each patient.

The research is still going on to improve the methods of educational diagnosis like how is made the diagnostic stage of education (terms and topics, frequency of update), how are the items collected during this step to customize the program proposed for each patient (calibration in terms of number sessions, speed sessions, individual and group training, etc.). It will help to the tentative plan overall program (average length of a total program hours for a patient, average number of sessions per patient, frequency, etc.) and to find the main

objectives of each individual session or group of TPE and to find also methods and techniques of teaching and support used (e.g. handling of medical equipment, role plays, resolution of problem situations, practice a structured physical activity, group speech, interview counselling, telephone support, etc.) [3].

The first thing the cancer patient needs is the correct way of announcing the disease to him and to stabilise him so that he can be mentally in a situation to understand well the disease, treatment and then be able to participate. After the efforts of "League against cancer" this is done in a special way now. The cancer patient during and after the announcement needs a well psychological support so that he can be prepared after to fight against his disease with the help of professionals and can follow the therapeutic advices. Patients with cancer on chemotherapy need the therapeutic education specifically to deal with the side effects of drugs like nausea, vomiting (and how to modify their way of eating to avoid nausea and vomiting), anaemia, bruises, alopecia, adjustment of doses if they are taking pills, sessions of chemotherapy and care of central venous catheter. Cancer patients also need education to deal with: pain, adjustment of the timings for chemotherapy, daily family life, social life, reproductive life, professional life, bank loans, stigmatization, sexual life, stage of disease, recurrence of disease, co morbidity, some understanding of the results of laboratory tests (as the deficiency of blood cells is one of the complications of chemotherapy and can be very alarming), nutrition, weight check, stress, infection, fatigue, skin problems, how to change the sleeping and resting hours to avoid the tiredness.

During the educational-diagnosis, we should take information how is he living, all details of daily life, educational and IQ level, his eyesight, hearing, talking, language, cognitive understanding all are needed to be assessed so that we can plan an individual program for him. We should be careful about learning difficulties (e.g. problems with reading and understanding, sensory or mental disabilities, cognitive impairment, dyslexia), socio-economic class, cultural and educational background, and place of residence should also be considered[14].

The patient's ideas and beliefs need to be known and understood (if wrong try to change). This is not to judge the patient on cultural or religious basis but to help him to cope with disease. Educational diagnosis should be very fair. Each recipient of a program must be treated in strict observance of the principle of non-judgmental, especially about its cultural identity, their lifestyles, their ideological affiliation, spiritual beliefs, practices in health, his risk-taking and sexual orientation. Support of the whole person, the diversity of determinants of health, genetic, psychological, social, cultural, economic, political, geographical and environmental is recognized and must be taken into account in the activities of educational diagnosis.

Each patient gets different problems so will get different therapeutic education according to

the educational diagnosis to deal with all these side effects[15]. It is never definitive once done. It will be changing with any matter changing with a patient.

Psychological support is the most important thing during educational diagnosis. Different patients responds differently .We have to identify the patient's needs, expectations, and willingness to take up TPE. Evaluate the patient's personality, lifestyle and potential to take their needs and life projects into account. See how they react to their situation and determine their personal, social, and environmental resources. We should not forget to assess the patient's proper access, response to needs and expectations, choice of techniques and teaching aids according to the patient preferences like Brochures, TV, internet, theatre (plays) puppet shows, educational sessions, consultations, group discussions during chemotherapy[15].

Cancer patient care included different steps of treatment, an acute phase and then a surveillance phase. Each patient may get one, or the combination of therapies like radio-therapy, surgery and chemotherapy, depending on the type and stage of cancer. So educational needs of the patients can be changed during the process of care. The educational diagnosis should comprise the periods before, during and after the treatment; taking into account his daily life as a must.

Methods usually used to have educational diagnoses

Interviews, psychological technique, questionnaires, chart review and tests

RESULTS

Process of care at University hospital Rouen

Patient comes with symptoms to the specialist doctor in the hospital, usually referred by a family doctor; after the investigations are done. If the provisional diagnosis is cancer, the case file goes to the RCP. A team of specialised doctors decide about the final diagnosis and treatment. It is announced to patient during a special consultation by the professor or the doctor, at the same time the treatment is explained to him.

It is observed that each patient has his own individual situation like one patient can be already hospitalised for investigations and during the investigation the reports may reveal that he has got a cancer and then it is to announce in the hospital during admission. It was learned from one hospital meeting that 95% of the patients got their diagnostic announcement during hospitalisation while other 5% got it during consultation.

Announcement consultations about the cancer diagnosis or any change for therapy, the change of disease stage etc

The patient comes to the doctor with or without someone with him; the patients are encouraged to come with some close friend or the life partner or any other family member so that at the same time he can listen and can help the patient afterwards morally and in the understanding of education.

Doctor, who has already prepared the content of his consultation, after studying thoroughly the medical reports and radiological examinations, starts with informal conversation. He tries to know what patient already knows about the diagnosis. He uses very careful words to announce" I am afraid that it is something serious" then takes time to see the reaction. Respecting the patient's reactions, he explains about the diagnosis.

Then explains, with or without diagrams the physiology, pathology, why and how the normal function was disturbed, what could be the reason, try to have all the detail of the family history to know whether this is genetic or not or it was induced by the profession etc.

The doctor always tries not to use the medical terms. Talking to another person, discussing technical problems, showing surprise in front of the patient, can disturb the anxious patient attentively watching the doctor's face and interpreting his/her every reaction only tend to increase the patient's anxiety[17]. The doctor is supposed to be careful about all these aspects.

He explains well about the treatment and the stage of disease, possibility of being treated, type of treatment like surgery, radiotherapy or chemotherapy according to the type, stage, general condition and co-morbidity of the patient is then proposed him one or a combination of different therapies. The patient is told accordingly about the side effects of the chosen therapy and is encouraged to participate in the decision making for choice of treatment.

At the time o f the diagnosis and after this consultation, the patient's recourses, barriers and learning needs can be assessed. Many patients are not receptive to education just after this diagnosis announcement since the diagnosis can trigger a crisis. Most patients need repeated education, both because there is a large amount of information to be given and because the patient's condition and treatment can change over time[16].

This first step also includes an assessment of the patient's previous knowledge, misconceptions, learning abilities, learning styles, cognition, attitudes and motivation. During this consultation it's not always possible.

Reactions of the patients to this news

Six consultations for announcements of cancer diagnosis were attended. During breaking the news the doctors are very much concerned about the reaction of the patient as different patients react differently. Some are shocked and some already have an idea about the diagnosis as some other professional in the hospital has already told them. The personalities and the education level also matters for the reaction of the patient. Some participate in the discussion, some are totally lost, some gets euphoric, some gets furious and violent and

some cry (see annexes Table 1). Sometimes the consultation has to be stopped. It was told that sometimes a nurse is also present during this doctor's consultation, but it was not observed.

Example of two patients:

Patient1, A 60 years old man diagnosed for the lung cancer during his admission in the weekly hospital. No family member or friend was there. The news was broken to him by a junior doctor. The patient stayed quite at start and then he started crying. The treatment and the side effects were described to him. The patient was given moral support. After this the coordinating nurse asked him if he wanted she would give her a consultation for *Classuer* use and intravenous chamber implantation or about any other question. He was offered this consultation after some hours so that he can have some time to collect himself. She said it would be better if somebody of the family could be present. He said that in the evening his son was coming and then it would be suitable to meet her again.

Patient 2: Another patient 86 years old accompanied by his wife, with very positive attitude took part in the conversation in an outdoor consultation. He was diagnosed with cancer of liver. He told that he was already sure as all his 7 siblings got cancer and three of them had died in very old age except one brother who died at the age of 50, he was alcoholic. The doctor drew his family tree and gave the information about his disease and chemotherapy he was about to undergo.

Six other consultations were also attended for the breaking up of other bad news related to cancer apart from the first time cancer diagnosis.

First consultation was for an outdoor patient for the change of therapy. The patient was with his wife and was told that as his cancer is not responding well to chemotherapy so they are planning to have a massive surgery. The patient was upset but was trying to understand. The wife was more involved to have the information.

Second patient was consulted for the recurrence of disease but he was not showing any concern, only giving the impression that all is good now and it's not possible to have the same problem again. He was alone.

One lady with pancreatic cancer came to discuss the schedule of her chemotherapy sessions, as she wanted to go to the marriage ceremony of her grandchild. She wanted to have a pause for chemotherapy. The lady was accompanied with her son and daughter in law. They were very much involved for the information.

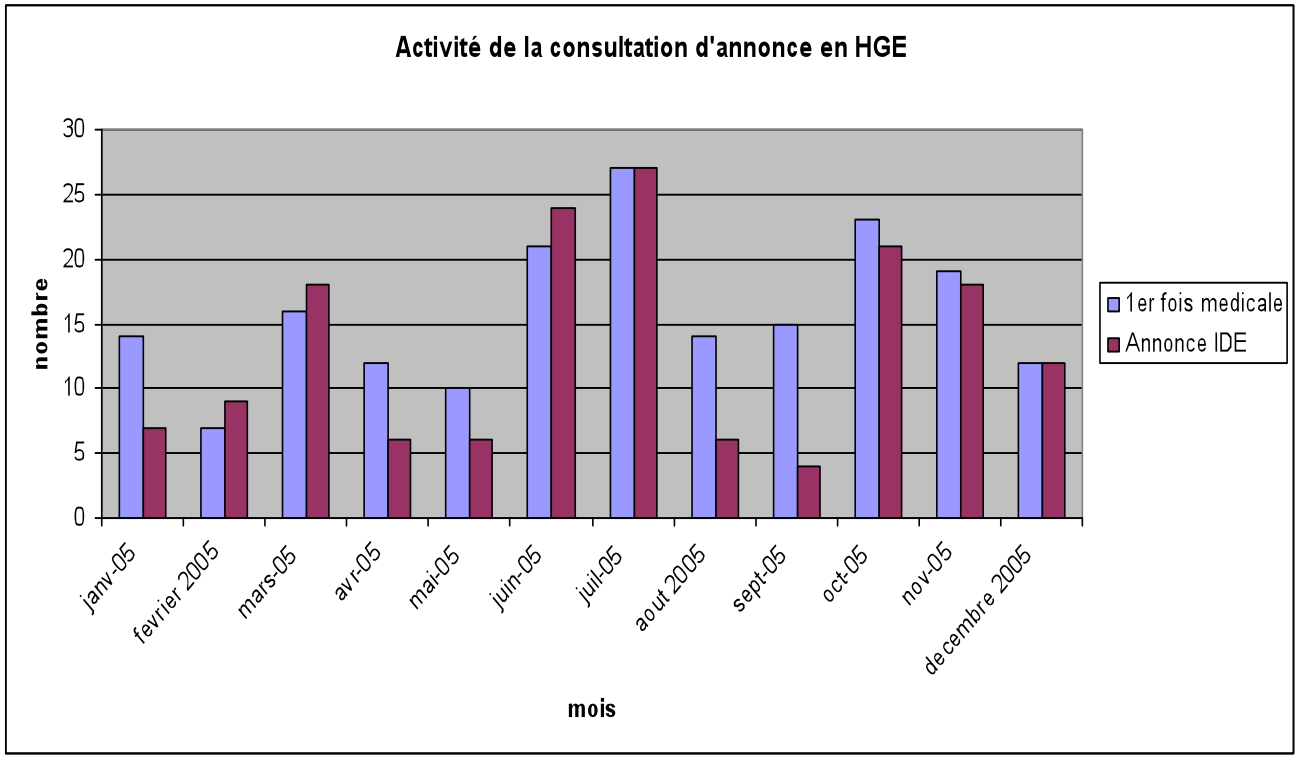
One person 70 years old came with a friend .He was diagnosed with diabetes now and was having the cancer of intestines already. He was given the new information how to cope with two diseases at the same time.

One patient with cirrhosis of liver, alcoholic put on weight and was advised by the doctor for diet and to have help to reduce alcohol intake.

One young patient with stenosis of esophagus, now better, was advised about his annual checkups to have prevention for esophageal cancer. The doctor advised how to apply and get bank loans. The doctor discussed about the stigmatisation against cancer patients resultantly they face problems like bank loans etc.

The sixth young lady of 53 years in very good general condition came with her daughter. She was told that the size of her metastatic lesion in her lung had responded very well to chemotherapy so all was fine to continue the present therapy. All the radiological pictures were shown to her.

Fig1: Activity of announcement consultation in hapetogastroenterology department



The fig is taken from hospital's informatics

Just after the doctor's consultation, there is a nurse consultation (the doctor decides which patient needs this consultation) sometimes, which explains well to the patient about the intravenous chamber, she shows it to him, how to take care of it, treatment and also side effects if patient wants to know. She also explains to the patients whom he is going to meet in future like dietician or other involved professional. And sometimes if patient cannot understand well about the disease that is explained already by the doctor, the nurse explains it again. It is important to be aware of various barriers to the understanding for patient, for example: stress and anxiety (especially at diagnosis), psychosocial or emotional factors, poor communication between patient and provider, poor literacy (affects communication as

well as reading), physiological aspects - of the disease itself, or treatment. Some of the fundamental flaws in patient education strategies arise directly from a mismatch between the views of patients and health care providers. The nurses are provided with an organised document describing how to receive the patient and what factors of the patient are to be analysed like their reaction of anxiety or fear, tiredness, nutritional deficiencies, lack of a care giver or any other change etc during this consultation and what to tell him about like disease treatment, life, environment e.g. family, social situation, projects of life and also about the development of the situation. This document called *MACROCIBLES " compte rendu de la consultation infirmièr d'annonce" S*ummary of the Nursing Consultation of announcement.
Seeing the deep involvement of the psychiatrist with hospitalised cancer patients and after reading literature about Oncopsychology, it was asked from one psychologist that can't he do the announcement consultation as it will be helpful for patient to have a psychological support at this tender moment. He replied, "I am not recognised as a medical doctor and does not know much about medical aspects of cancer but after whenever patient needs me I am always there for the consultation". The same question was asked from the psychiatrist and he said that he was a doctor but not specialist in oncology so let specialists and medical doctors to do it and after we were there to help.
So if we can develop the field of Oncopsychology and involve them in announcement consultation, may be it won't be so painful for patient to listen about this diagnosis for the first time

There are three types of hospital wards for cancer patients.
Day hospital where they come for some hours, see an intern or a doctor, already with fresh blood reports, if the reports are ok the chemotherapy session can be started, if not he is advised accordingly and on the same day he goes back. These Patients are usually in better general condition, can come to hospital and deal themselves at home. During chemotherapy session, the dietician also comes to take their weight and to advice accordingly. In the gastroenterology department the office of *assistante de suivi* (Assistant Monitoring) is in the same place so if the patients have some other problem like social or administrative they can ask for an appointment with her.
In the weekly hospitals, the patient comes for more than one day and is discharged within one week. The traditional hospitals do not have the limit of the days. The patients are usually not in a good general position and undergo different investigations or change of therapy etc.
Accompaniment of the cancer patient
One of the measures of cancer plan is accompaniment of the cancer patient .*To achieve this goal, these* patients are followed by a coordinating nurse (in Pulmonology department) or by

the attending assistant (*assistant de suivi,* in oncology section of Urology ward and Gastroenterology). The later is a special post that has been created under the cancer plan. After admission, one of these mentioned nurses explains the classuer to the patient and his disease. They work like a chain between patient and all other professionals. She takes the consent of the patient after explaining treatment; it's duration and side effects. She also takes the consent that his medical information can be used for research. She fills a special Transmission Form about the patient's needs and psychology and keeps in his medical record.

RCP's (Multidisciplinary meetings)

These are the special meetings where all the specialists like medical specialist, surgeons, radiologists and other medical-staff is present. The interns or the junior doctors present their cases in detail to these professors and the final diagnosis and treatment is decided. The coordinating nurse and *attending assistant* are always present there to take notes for patient.

Daily and weekly meetings

During the daily meetings of giving the charge of patients to each other, the medical-staff discuss the different aspects of patients. In the week and traditional hospitals, there is a special weekly meeting of all the professionals involved. This is a good place to have an exhaustive discussion about the patients. Each professional is present there to discuss about the specific needs of the patients. These are the professionals who already have given the detailed consultations to the patient. The social assistant, dietician, psychologist, doctors, interns, nurses, midwives and secretaries all are present. They discuss about all the aspects of each and every hospitalised patient in cancer ward in detail. Here are some examples about the issues which were discussed like, the hesitation of some families for chemotherapy was mentioned, financial and personal problems, problem of acceptance of 16 years old granddaughter about diagnosis of cancer of her grandparent, the problem of cancer patient's wife who was also his caregiver and also had a handicap son at home, psychological problems like patient X was talking too much about other things but not about his disease (escaping behaviour), shifting of patients in the other hospital if there was some problem here, also about the pain and change of dosage of morphine for patient Y, dietician advised for patient W fractioning the meals to avoid vomiting and also to eat cold food to avoid nausea so that the smell of food can't disturb the patient. Social assistant offers help for financial or social problem, administrative help like the change of *caisse* (local social insurance office), for the job retention and return, home support for patients, patients' access to loans and insurance, also for the matters like access to patient groups and users in the hospital whose psychological, recreational and assistance actions are important for them.

It was noticed that for every member of the meeting the social ties of patient were very important.

Classer

These are the special WORKBOOKS used in the oncology department of Urology and Pulmonology. In this work book we can have each detail of the patient, his signed consent, the dates for his appointments with doctors and chemotherapy sessions, all the contact numbers, addresses of all professionals who will be involved for his care, the side effects of chemotherapy, advices how to cope with side effects, information about cancer in general and also there is a big space left for him to write questions if he has during all his therapy. He is supposed to bring it during each visit so that the doctors and nurses can see it and can modify educational diagnosis.

Project Meetings of hospital staff working for the elaboration of TPE programme

The meetings are conducted for the elaboration of TPE with different hospital workers like pharmacist, chiefs of the nurses, *attending assistant*, and psychologist under the supervision of Prof. Czernichow to discuss what is already going on about therapeutic education for cancer patients and how can we improve it.

Another meeting was organised every month with the head of departments of different specialities to discuss about the financial matters and capacity building for the elaboration of TPE in the hospital for cancer patients. The head of diabetic and asthma centres were present there to share their experiences about already existing TPE programs in their departments.

It was agreed to clarify to what extent educational activities should be introduced in the establishment and also to check the conditions of these activities (mandatory requirements) to start this program.

The establishment of a special document for therapeutic education was recommended.

A working group was recommended to develop a method for educational diagnosis. Some of the heads were not satisfied with the progress of this program.

The educational training course of professionals for TPE

One educational course was conducted for seven months from November 2009 to June 2010 comprising of twenty six sessions of the whole day. The workers of different medical fields from all over the Seine Maritime were allocated to have training for all the four stages of TPE for any kind of chronic diseases not specifically about cancer patients. Two sessions of this study course were attended and it helped to understand the idea and functioning of TPE.

Interviews with cancer patients

Seven patients were approached to request for an interview. Four patients declined to participate as not willing. The 3 patients who gave verbal consent and were asked questions, all well participated. The age range of the participants was 56 to 80 years, with a mean of 64.5 years. One was woman, and all were married. Two male patients had Lung cancer and the woman had colorectal cancer. The women got her diagnosis two years back and for men it was less than six months.

The first patient was on chemotherapy since last six months, she was cooperative and took part in the conversation. She was highly educated .She was interviewed during chemotherapy in a day hospital.

She was satisfied with all the explanations from doctors about the disease. She thought private sector manages education in a better way, as there were more nurses for less number of patients. The answers of the questions are after mentioned in the table no.2 (see annexes).

Patient 2 was old man, very anxious, diagnosed with rapidly progressing lung cancer related to his profession, not happy with the nurse's behaviour, was talking a lot about all other matters a part from his disease, was admitted in the weekly hospital to have final decision about treatment, currently was on chemotherapy. He was angry that he could never understand what the doctors were telling him about treatment, as he is unable to understand the medical language that they use. He said that whatever the doctor advice will have to be accepted. He does not know about medical things. He said he has never opened the *Classeur* it's just useless for him.

Patient no.3 He was an old man, diagnosed with lung cancer, very calm, told that he is not willing to know each and every thing. I know whatever the doctor says is good for me so everything is acceptable. He remarked, "I am already 80 years old and everyone has to die of something, no use to go into details of anything, whatever doctors and nurses say I only follow". He said that he had never written any question on the *classuer.*

Interviews of professionals

The questions and their responses are in the table 3 and 3a given in the annexes.

None of them have got the training for TPE. All are agreed that as a method for educational diagnosis, the personal interviews are the best option. Six of them (55%) did not know about educational diagnosis. Only one did not like the idea of TPE (9%). Eight (73%) of them believe that ED should be finalized during the next weekly meeting after having a detail consultation of them with patients while rest said it should be done during chemotherapy sessions. Five of them (more than 46%) are convinced that *Classeu*r can help as a part for educational diagnosis while three thought it can't, four (36%) of them are convinced that

patients can understand about disease and therapy. Six (55%) of them have the experience of patients asking questions. For participation for decision making five (45%) of them told that some of participate in the decision-making.

Consultations with Psychiatrists

One consultation was attended with psychiatrist and senior doctor for a woman, her mother got cancer and it was very difficult for her as she was the care- giver as well. She spoke about her psychological situation and also of her mother how her mother wants to have physical contacts with her like kissing her. This lady was 56 years old and was well educated. One of her sister worked as nurse and was a great help for her to take advices for dealing with her mother.

The very important character for educational diagnosis can be psychiatrist and psychologist. The psychiatrist put emphasis on the personal interviews as the best method for educational diagnosis. They really were in deep contacts with patients and could explain well the educational needs of the patient. The patients are referred to psychiatrist if they demand if not it's not mandatory .The psychiatrist plays an active role by visiting and putting his notes about patients. He was involved with families as well.

The psychiatrist was also observed staying with patient and his family during his terminal stages. He was adjusting the morphine dosages and was busy to give psychological support to the family of dying patient.

Discussions

This paper contains two parts: the knowledge from literature reviews and the observational part. The main purpose was to identify the best method and timing to know the educational needs of the cancer patient that calls educational diagnosis. The ED is first and basic step of TPE to formulate an adjusted individualized program to give him more knowledge, skills and empowerment to take part in the decision-making and to get the ultimate goal of better health for him while facing a chronic disease like cancer. This paper will contribute to the elaboration of a new TPE program for cancer patients that is in progress under the supervision of Prof. Dr. Chengchow Pierre; the head of the Public Health and Epidemiology department in Teaching Hospital Rouen, France.

The literature review helped to understand the global view of TPE, its need, good effects, the lessons from experiences of TPE in asthma and diabetes, it's need for cancer management, and to understand the concept of educational diagnosis and steps involved to have it. It was also helpful to formulate the questionnaires and to have an idea which parts of the hospital functioning and health care process of cancer patient can be closely observed to have some conclusion.

The objective of second part “the observation” of hospital activities was to find which part of care process has the capacity to integrate this new part of therapeutic education in an already existing process of care, which time is the best to get an educational diagnosis and also the best method to conduct it. This qualitative part mostly comprises of the observations of two cancer departments of Teaching Hospitals of Rouen. It includes attending the medical consultations, following of the medical staff, interviewing the patients and professionals involved, consulting the medical records and *classeurs*, attending all the meetings going in routine and also the project meetings for the elaboration of TPE.

There is very little information available about the methods and timing for ED in the literature so it was preferred to get information by the observation of health care process for cancer patients particularly those on chemotherapy and also to get ideas by direct interviews from the patients and professionals involved, what they think about this after having experiences with cancer management journey.
A small part is about the interviews of only three cancer patients and 11 professionals of different medical approaches involved for cancer patient’s care. This part of data is incomplete as is not very exhaustive to reach to a very definitive result about the timing. The family and friends that is a vital part of this diagnosis making could not be included due to the time constraints, that left big gap to go to a very authentic conclusion.
The observation was tried to do chronologically from the first day of patient’s contact with hospital and to make a sequenced story of all the journey of patient during this care process in the hospital.
For this purpose the first thing was to consult the medical records of the patients. These are big files of cancer patients with all their treatment and examination histories the professionals’ note the family doctor’s references and the results of radiological and other investigations. All were used to understand the history of disease prognosis and the care process with dates, so it gave an idea of chronological information of whole health care process and also about who was involved at which time. The *classeurs* (medical work books) whether patients were taking interest to fill it or not, only one among three was observed filled in a proper way by the patients, others were incomplete and patients never used them.

The most important part was attending the consultations of the doctors with patients for announcing the bad news to them. In past the cancer news was broken to the patient without taking any precautions; it was just like to give any other information. Un favourable news in the medical context has been defined as “ any news that drastically and negatively alerts the patient view of her or his future” In the literature most of the recommendations have typically been written from the physician’s perspective, with less attention focused on the patient’s

perceptions and preferences. Because giving unfavourable news is a two-way communication between the physician and the patient and because the patient is the one whose life is directly affected, it is particularly important to consider and understand the patient's perspective on the communication. Now it's told in an organised consultation after the struggle of an association "League against cancer" and is a part of cancer plan.
According to one of the study, protocols for breaking bad news to patients, such as SPIKES (an acronym for a six-step protocol for breaking bad news that has been used successfully in communication skills workshops conducted at The University of Texas M.D. Anderson), are likely to meet patient's expectations for bad news disclosure. For example, the S of the SPIKES protocol represents Setting up the interview and corresponds to the Facilitation subscale of the MPP. The K of the SPIKES protocol represents giving Knowledge and information to the patient and this is similar to the Content subscale or information dimension. Similarly, the E in the SPIKES protocol stands for addressing the patient's Emotions with empathic responses, which is similar to the Support subscale of the MPP. Importantly, what is being taught to physicians about how to deliver bad news corresponds to the areas that patients believe to be important[18].
In the teaching hospital these consultations were attended and was observed that they were following the SPIKES even some of them did not know about SPIKES. At the end of the consultation the messages were recorded on the audiotape to send it to the secretary to type and to send all the related medical staff.
One thing was noted that the patients were not given the aide of some audio- tape or paper pencil facility to note all the information, yes it's true that after the shock of this news it's difficult to write or may be some patients are unable to write but the accompanying person could do it or maybe not. So either the audio recording can be provided to them or pen and paper according to the patient's wishes. No means were utilised to show some pictures or drawings to the patient about pathology or treatment procedure that could have made it easier for the patient and the caregiver to understand.
In author's opinion the patients who are shy or do not want to know due to their personality or the psychological state, they have the equal right to have an access to the information for their care and also to know well about their disease. There should be some way found to convey the information to them so that without being conscious of the teaching they can be educated in an indirect way and will be able to handle their disease like brochures small booklets etc. The professor was asked about this, he replied that there was a nurse consultation after this consultation so the patients who were shy would ask from nurse as sometimes they took the Professor doctor as some "big man" and hesitated to ask.
The after wards nursing consultation was given to the patient only if the doctor advised. Like once I spent the whole day with the nurse but doctor did not sent any patient to nurse for this

consultation so not all the patients get this second consultation. Everybody included in this observation is convinced that this is not a good idea to talk about therapeutic education just after this shocking news. So this nurse's consultation can be delayed.
All the doctors told that they never had any training for ED and TPE, as no special training so everybody does in his own way. One remarked " I learned it from my heart". The others said that they learned by their practice. Some were not really good at conveying this news. The whole medical staff t told that they did not get any training for TPE. Some of them did not even know about ED.

The nurses involved were followed for the whole day to see how they deal with hospitalized cancer patients. During this follow-up it was observed that in a Teaching Hospital of France, the TPE is going on already in an informal way. It could be felt in the hospital environment. The situation is already good for therapeutic education but needs to be formalized. Every patient is getting therapeutic education during consultations from the doctors and the nurses all the time. The doctor spends 30 to 45 minutes in the consultation and can answer well to their questions. During follow up of the medical staff, it was well observed that the medical staff was discussing about their patients with each other informally, so it is very good to transmit the information and educate them accordingly.

All the professionals are interlinked with the letters those are typed after the professional's recording messages on the audio-tapes .It is also sent to the family doctor that is the basic stone of patient care.
In hospital during the consultations and meetings with medical staff, everything looked perfect, as everybody was concerned with every aspect of cancer patients, their discussions about them were in detail, they were transmitting the information to each other and to the seniors well in a competent way.
In contrast, during the project meetings for the elaboration of TPE, with the heads of departments, the situation seemed very tough like one of them mentioned in one meeting that nothing is going well for education, patients are not interested, the staff is already busy so most of the time it seems very helpless, practically it's not going on, only two or three patients are there in her department who are taking part for this. She expressed UN satisfaction, as she thinks it's a very long process.
It was encouraging that the educational training courses were organised for medical staff to learn about TPE. It's a very good initiative.
The daily and weekly meetings and RCPs were attended. RCPs were very impressive as all the brains were present there to give the best diagnosis and discuss about the treatment with very little chance of mistake as it is well negotiated among all professional of high level. The

presence of coordinating nurse and *attending assistant* make it useful, as she then is aware with whole treatment and diagnosis to deal with patient after.

The weekly meeting is the most important meeting. A panel of multidisciplinary professional sit together on a specific day in a week. The very important thing about this meeting is that all these professional are already have detailed consultations with a patient. Here they discuss and give new orders according to the needs of the patients.

The patients admitted in the weekly and traditional hospitals has this useful platform to have finalised their educational diagnosis to have an adapted educational session but it should not be forgotten that it can be changed any time.

To finish this discussion last thing that I want to share is what the psychiatrist pinpointed. He narrated about one female patient, 38 years old, having two children of 13 and 9 years old, the husband is already died of suicide, how to educate this patient who is only worried about her children. The big question for her was what will happen with them after her, who will look after the children. The mother died in three months time. What the therapeutic education means for such patients, she did not want to know anything; she was only worried about her children and her every question remained always about them.

Another patient 42 years old, well educated, from a very good social class diagnosed for the first with metastasis to brain and lungs. I tried to interview him; He said," I don't want to know Anything as I already knows that I am going to die in some days so leave me alone to watch TV on my deathbed.

One young patient, responsible for the whole family, at his terminal stages, taking his last breaths, very un comfortable, the psychiatrist was there, he said something in his ears and patient closed her eyes smoothly and took his last breath. He told us that he just told the patient that all we were here to take the care of his children.

Conclusions

Time for Educational Diagnosis:

Still very unsatisfactory, each patient is unique, it's not easy with only small observational study and qualitative data that we can have a definitive answer to standardise the timing for educational diagnosis. One thing for timing was confirmed by patients and professionals that it should not be just after the diagnosis announcement consultation as it's very difficult for the patient to learn just after such a drastic news. The most appropriate time to start extensive education and to have a diagnosis for that is when the patient is in a stable condition and has started to adapt to living with cancer.

According to my opinion after the observation of the whole process of care for hospitalised cancer patients, and after having the interviews with patients and professional, one idea has been caught that the educational diagnosis that is a multi-disciplinary decision can be finalised in the next weekly meeting where all multidisciplinary professional are present who already have detailed consultations with patients. However, the educational diagnosis is constantly reviewed during the patient journey and could evolve depending on changing situations.

The ENTOURAGE of the patient could not be included in the interviews because of the time constraints that have left a big gap to reach to a conclusion.

More work and research is required to get a final conclusion.

Method for Educational Diagnosis:

We got 100% agreement of all the professionals and patients that personal interview is the best method to have Educational Diagnosis.

Limitations of the study

It was difficult to have an access to the patients for interviews, as most of them were not willing. Some of them were under chemotherapy already, not having good feelings because of nausea; only one interview could be done during chemotherapy session.

The author had to wait long hours to attend some consultations or even some days as sometimes there were only few announcement consultations during the week. Emotionally it was difficult to observe this consultation.

Time constraints: only ten days were not enough to get data on such a subject.

Due to the time constraints the relatives and friends were not interviewed who are very vital in having the information about patient and making educational diagnosis.

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Abstract in French

Les progrès médicaux du Siècle dernier ont permis de mettre l'accent sur les maladies chroniques. En sus de la prise en charge technique, les patients qui vivent avec des maladies chroniques nécessitent généralement une prise en charge de long terme et une continuité dans les soins. La plupart des maladies chroniques nécessitent également une prise en charge curative mais aussi préventive. L'éducation thérapeutique pour le patient (TPE) est reconnue comme l'un des meilleurs outils pour prévenir les complications et faire de la qualité de vie du patient un élément essentiel de prise en charge. Des programmes existent déjà pour le diabète et l'asthme. Un programme de même nature a été initié à destination des patients cancéreux par le CHU de Rouen. L'équiped'éducation thérapeutique travaille en étroite collaboration avec les acteurs des Rencontres médico-psycho-sociales.Quatre étapes structurent les TPE. Le premier est l'éducation au diagnostic : élément de base pour construire un programme éducatif à l'attention du patient.

Objectif:

Repérer le meilleure moment et la méthode optimale pour initier l'éducation au diagnostic et la chimiothérapie à destination des patients cancéreux hospitalisés.

Méthode:

Cette étude contribue à l'élaboration du programme en question. Le processus de soins a été observé au sein de l'hôpital de Rouen pour les patients atteints de cancer. Le suivi s'est fait chronologiquement dès le premier jour de leur contact avec l'hôpital. À cette fin, des documents médicaux des patients ont été consultés. Les consultations dédiées à l'annonce de la pathologie, ainsi que les réunions liées au fonctionnement quotidien de l'hôpital ont également été suivies. De plus, les réunions de concertation pluridisciplinaire ainsi que les réunions hebdomadaires du staff ont contribué à l'étude. Enfin, des entretiens individualisés de patients et de professionnels ont été conduits afin de saisir le moment opportun et la méthode pertinente pour mener le diagnostic éducatif. L'étude s'est également nourrie de sessions de formation sur le TPE. Des réunions spécifiques de professionnels et de personnels de l'hôpital pour construire le programme de TPE ont également été observées.

RÉSULTATS

Tous les patients et les professionnels ont convenu que des entretiens personnels sont la meilleure méthode pour le diagnostic éducatif et que ces entretiens devraient commencer diagnostic éducatif ne doit pas être trop tôt après l'annonce de la consultation à cause du stress du patient. Pour le moment, les patients étaient incertains, mais parmi les professionnels de onze, huit ont convenu que le diagnostic éducatif devrait être finalisé après la réunion hebdomadaire.

Conclusion

Il existe un consensus raisonnable que les entretiens individuels où les patients rencontrent individuellement le personnel médical, sont le meilleur moyen de faire le diagnostic d'éducation, et est préféré par le patient questionnaires remplir. Le diagnostic éducatif est une décision multidisciplinaire qui aurait alors lieu à la prochaine réunion hebdomadaire. Toutefois, le diagnostic éducatif est constamment examinée au cours du voyage des patients et pourrait évoluer en fonction de l'évolution des situations.

Annexes

Table 1: Reactions of the patients on diagnosis announcement in Teaching Hospital Rouen oncology department

RESPONSES OF THE PATIENTS	CRYING	EUPHORIC	UNRESPONSIVE	INVOLVED	VOILENT
Patient 1	yes		yes		
Patient 2			yes		
Patient 3		yes			
Patient 4				yes	
Patient 5					
Patient 6			yes		

Table 2 Questions and the responses of the patients during the interviews

QUESTIONS	PATIENT1	Patient2	Patient3

1. Introduction to the patient?	participated	participated	participated
2. Informal questions to start conversation?	Participated	Very talkative	participated
3. How did you know about your disease?	By the dr. at hospital	My wife told me before going to announcement consultation	Radiologist
4. How did you react?	I cried	I did not believe	I accepted
5. Could you understand all the things that doctor told you after the announcement?	no	Not at all. They speak medical language.	Some of it but I don't care
6. Did you like the way it was told?	Yes, they were sympathetic	No, they are not kind	yes
7. After how was nurse's consultation?	I was still in shock	Same jargon	good
8. Could you understand each and every thing?	Little bit	Not at all	yes
9. Someone was there with you when you heard about it for the first time?	My husband	My wife	My daughter
10. At what time should we start the sessions for educational diagnosis?	After some days	I don't have any idea, I am not a doctor.	I don't know
11. Do you take part in your decisions about your treatment?	Yes	I accept all that is told to me.	No, doctors are responsible to make decisions.
12.Did you get every information about the side effects?	yes	yes	yes
13. Are you satisfied with the treatment?	yes	no	Yes
14. During chemotherapy would you like to have the	No, I feel nauseating	yes	yes

interview?	and don't want to talk		
15. Could you understand the *classer*?	yes	no	no
16. You find it useful? Do you write your questions on it?	Yes, always	None, I never write questions on it.	None, I never write questions on it.
17. Do all the medical staff satisfy your question?	I ask a lot and they answer	No they are not nice	yes
18.Have you ever had a Special educational session about your disease a part from announcing consultation?	no	no	no
19. What do you think which method is better to do educational diagnosis questionnaires or interviews?	interviews	interviews	interviews

Table : 3a Questions

From professionals with answer codes				
1. Have You got the special training for TPE OR Educational Diagnosis				
No =0	Yes =1			
2. What is Educational Diagnosis ?				
I don't know =0	Iknow =1			
3.Do you like the idea of TPE?				
No =0	Yes =1			
4. At what time should we finalise educational diagnosis?				
Just after the diagnosis announcement =0	during RCPs = 1	During weekly meetings =2	during chemotherapy sessions* =3	
5. Is *clausser,* the good way to analyse the patients educational needs?				
No =0	Yes =1	It can help =3		
6. Which method is better for educational dignosis ?				
Questionnaires =0	personal interviews =1			
7. Do they try to understand whatever you tell them about disease and therapy?				
No =0	Yes =1	some of them =2	a lot of them =3	I don't know =4
8. Do they ask questions ?				
Not at all	All of	some of	Most	

=0	them	them	of
	=1	=2	them
			=3
9. Do they participate for making the decisions for their treatment?			
No one	All	Some of them	
=0	=1	=2	
10. Do you have an official order for you to do the TPE or Educational Diagnosis?			
No	Yes		
=0	=1		

Table :3b
Responses of the professionals with answer codes

Q	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11
1.	0	0	0	0	0	0	0	0	0	0	0
2.	1	1	0	1	0	0	0	1	0	0	1
3.	1	1	1	1	0	1	1	1	1	1	1
4.	2	2	2	2	2	2	2	3	3	2	3
5.	0	0	3	0	1	1	3	3	3	3	3
6.	1	1	1	1	1	1	1	1	1	1	1
7.	0	0	0	1	1	1	1	2	2	4	4
8.	2	2	3	3	2	3	2	2	2	3	3
9.	2	1	2	0	0	2	2	2	0	1	1
10.	0	0	0	0	0	0	0	0	0	0	0

P (Professional), P1, P2, P3, P4 (Doctors), P5, P6 (Nurses), P7 (Psychologist), P8 (Psychiatrist), P9, P10 (Nursing chiefs), P11 (Coordinating nurse)