



UNIVERSITÀ DEGLI STUDI DI PALERMO

Dottorato di ricerca in Oncologia Clinica e Molecolare
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Exploratory study about needs of disease progression in cancer patients

IL DOTTORE
Samanta Battiato

IL COORDINATORE
Prof.ssa Giuseppina Campisi
DISCIPLINE
CHIRURGICHE, ONCOLOGICHE
E STOMATOLOGICHE
Dottorato di Ricerca Internazionale
in Oncologia e Chirurgia Sperimentali
Coordinatore: Prof. Giuseppina Campisi

IL TUTOR
Prof. Giuseppe Cicero

INDEX

Abstract	1
Introduction	2
Aims of the thesis	11
Materials and methods	13
Results	18
Discussion	22
Conclusion	25
References	26
Attached	34
Poster	35

Abstract

Background: Oncological disease progression can be difficult to manage for physicians, due to therapeutic switch after a previous treatments' failure, but also because oncologist have to be linked with information about clinical conditions for patient reassurance. Our research considers person an integrated system, looking at fundamental needs of patients, according to theoretical and empirical basis of Neo-functionalism in psychology. Several studies report more unmet needs in patients affected by cancer, despite an increased attention about bad news communication. Previous studies in the field of healthcare have shown that both communication and psychological characteristics of patients are fundamental for the therapeutic alliance and satisfaction in care.

Aims: This study aims to explore emotional experience and psychological needs of cancer patients who have experienced disease progression. Specifically, the study investigates unmet needs and their associations with illness perception and quality of life.

Materials and Methods: The research included 61 cancer patients who have progressed after a chemotherapy. They have been undergone to psychological questionnaires to evaluate specific needs (Needs Evaluation Questionnaire – NEQ), illness perception (Brief Illness Perception Questionnaire – Brief IPQ) and quality of life (EORT QLQ-C30). Also socio-demographic data and informations on medical therapies are considered.

Results: Patients give greater importance to the empathic relationship with physician rather than accurate information about disease. Associations were found between factors observed. A patient who feels understood by the doctor has a positive illness perception and good quality of life. The need to be guided is the most reported by patients. Fragility in progression disease is accompanied by low illness control perceived, and greater delegation to the physician. The last result may be influenced by Sicilian cultural context, characterized by great caregiving

and ability to be guided. Moreover, delegation to the physician is higher in patients with low levels of education.

Conclusions: The results presented in this work seem to confirm that a greater knowledge about patient's specific needs of information, involvement, support, and associations with illness perception and perceived quality of life, facilitate care relationship in disease progression conditions. A good emotional contact is associated with less fear and more trust, so physician can guide patients also in difficult steps such as therapeutic switch after a previous treatments' failure.

Introduction

As every human experience, also illness involves not only body, but the whole person participation. In this specific case, oncological disease, with its countless difficulties, determines a continuous physiological modification of psycho-physical wellness: we can say it a complex "cancer experience" [1] which involves not only a physiological modification of the sick body (flipped-out cell), but also continuous alterations (both physical and emotional) due to collateral effects from treatments. Many researches about the stress linked to the event "illness-care" [2] distinguish an *External Trauma* (which is the amount of painful and invasive treatments) and an *Internal Trauma* (suffering from drugs collateral effects, such as nausea and hair loss).

The treatment of an oncological patient must have as its main aim the improvement of quality of life and the risk reduction of psycho-pathological diseases so important to condition a patient's future life [3,4]. Psychological difficulty showed during an oncological disease is not strictly linked to vulnerability or a personal psycho-pathological inclination, but to the specific condition of personal crisis brought by the disease. The disease experience

determines a psycho-patological condition of *alarm* that can negatively influence a patient's quality of life, medical care and survival [5,6,7].

Adaptation to disease and treatments mainly depends on the quality of the relationship with the medical *équipe*, who can build it by controlling collateral effects of treatments, pain, anxiety and depression symptoms. This is possible by an individual taking in charge of the patient, by the information on the different aspects of the disease and the evaluation of his/her needs, his/her possibilities of choice, his/her family and social conditions; this implies, inevitably, a personal involvement of the patient that can require an overloaded position [3,4]. The adaptation of the patient, in every single phase of the clinic procedure, is helped by different ways of communication that take in account not only informative aspects, but also emotional area. Hence, from the doctor side, a continuous dialogue and ability and availability to listen and understand some mechanisms of defense from the patient are needed, with the aim of understand unmet needs from the patient and adequately deal with them [3,8]. Satisfying specific needs is essential to reach and maintain a general wellness and a good psycho-corporeal functioning; this is, especially, crucial with patients who have experimented a disease progression coming from the failure of the chemotherapeutic treatment.

In literature there is some evidence that depression, anxiety and psychological distress are associated with patients reporting greater unmet needs [9,10,11]. If we pay attention to the specify needs of an oncological patient, we can be able to understand early alterations due to the *distress* of the medical procedure and to give to the patient an overall take in charge, so that it could give dignity to the body, often plagued by medical procedures.

A needs based approach to the delivery of cancer care has become an important focus, to ensure people receive care according to the complexity and severity of their needs, independent of diagnosis or prognosis [12,13]. Patient report measures have received considerable attention for their potential to improve healthcare practice, particularly given the low congruence between healthcare needs identified as important by health professionals compared with patients [14,15,16]. Research suggests that oncologists are often unaware or do not

establish a range of psychosocial, physical and informational concerns of their patients [17,18,19]. Identifying the characteristics of patients who are more likely to report unmet needs may allow better targeting of services. To date, younger age [14,20,21], living in rural areas [14,22,23], later stage disease [14,20,22,24], type of cancer treatment [14,22,25,23], time since diagnosis [14,20,26] and physical or mental quality of life [14,24,27] have been associated with greater unmet needs. Recent literature indicates that psychosocial concerns are becoming of paramount importance to many healthcare providers, including oncologists [17,28]. However, as Carlson [12,29] suggests, implementing care based on the assessment of needs has its own challenges, including how to define need and how and when to assess need. Therefore, the accurate assessment of these experiences and needs within the clinical setting continues to be a challenge.

Traditionally, resourcing for patients with cancer has focused on those with newly diagnosed and potentially curable disease. Many patients compare unfavorably the abundant support received at diagnosis to the dearth of support present at relapse. The present work concerns needs in oncological patients in disease progression phase, starting from the assumption that attention to the needs (information, involvement, meaning of symptoms, perceived distress) and experiences of the disease progression can give useful information to the oncologists to propose and manage a new therapeutic path.

Some authors say that physician empathy can indirectly affect depression and socio-emotional-cognitive quality of life through a desire for more information from physicians about treatment options and health promotion [14,30]. Recent studies indicate that patients with advanced, incurable cancer have high levels of unmet needs, especially in relation to the areas of psychological and medical communication/information needs. In cancer patient where the provision of treatment with curative intent is prevented [31,32], supportive care is paramount [31,33]: it can be viewed as a patient-centred approach to identifying and effectively responding to a spectrum of patient care needs [31,34,35]. Supportive care needs (SCNs) have been defined as requirements for patient care pertinent to the management of symptoms and side effects, enablement of adaptation and

coping, optimisation of understanding and informed decision-making, and minimisation of functional deficits [31,36]. Identifying and addressing such needs can well prevent patient distress, poor quality of life, and dissatisfaction with care [31,37], as well as resultant increases in health care utilisation and costs [31,38]. Some data in literature identify a range of unsatisfied needs reported by oncological patients.

Among the most urgent need expressed by patients and their families is for accurate and accessible information about their disease, standard and emerging treatments, realistic treatment goals, ways of coping with side effects and symptoms, and ways of communicating the news with loved ones (particularly children and partners).

Emotional problems were found to be highly prevalent [31,39,40,42]. As with daily living needs, these were more frequent compared to people with other health conditions [31,43,33]. Feeling anxious, worrying about being unable to control effects of treatment, feeling sad, and feeling a burden were the most common reports in the majority of studies [31,43,44,45,46,39,47,40,48,49,33,50,51,52,37,53]. Interestingly, patient anxiety was found to be related to low self-esteem and feelings that life is not worthwhile [31,54]. Moreover, guilt, fears about cancer spreading or returning, panic attacks, and fears about pain and physical disability emerged as frequent concerns [31,44,55,40,48,56,49,33,50,57,53].

Spiritual needs seemed to covary with psychological concerns at four transitional points: diagnosis, discharge after treatment, disease progression, and terminal care [31,58,52]. In this context, inability to find meaning and purpose in life, and concerns about the ability to keep a positive outlook and reprioritize the remaining time were common [31,45,57,52]. Patients reported of having concerns about death and dying [31,56]; such feelings were also reported to be overwhelming, but the thought of a “good death” occurring during sleep, and being quick and pain-free was considered to have a relieving effect [31,59].

Having a clinician to trust and available to talk about all aspects of their condition, treatment and follow-up in comprehensible terms [31,37,53], as well as feeling that professionals acknowledged their situation, were accessible and cared for them [31,50] were among the most pronounced support needs raised by patients with advanced cancer.

Concerns about the impact of illness on family members, about their worries, and about their ability to cope with caring for people with advanced cancer were frequently reported. Ability of patients to share their feelings within their support network was reported to be beneficial [31,60].

Some studies report that “understood” (in their needs) patients have a less depressive and linked to resources past and a better quality of life [1,2,3,5]. Functional Psychology [61,62,63,64,65] can help us to understand what happens when someone gets sick of an oncological pathology and what kind of needs, present since birth, can become fundamental to preserve and maintain a good quality of life even during disease progression.

Research has challenged a hierarchical vision of needs, who considers physiological ones as primary needs. Compared with the first studies on this subject [66], who distinguished primary needs, i.e. physiological needs for survival (such as hunger and thirst), from secondary needs, i.e. linked to relational and social area, the concept of need includes not only the satisfaction of hunger, thirst and protection, but also a wide range of experiences: heating, nourishment, curiosity, being hold, moving [63]. Furthermore, it seems that former primary needs could be satisfied within this new widen experience.

Functional Psychology [61,62,63,64,65] defines needs as “*directions*” where an individual moves to, to develop and grow up, even in disease. Since birth, people experience concrete situations to achieve these *develop lines* (Fig. 1).

Fig. 1



All these directions are fundamental needs to reach and maintain wellness. In every evolutive step, people concretely realize experiences coming from these specific needs and, even if every need is particularly worth in a specific moment, their influence is unchanged for a lifetime. E.g., Being Hold, Being Nourished, Being Loved are fundamental during childhood and not only for survival; so, a child very often experiences actions with the aim to satisfy his needs, even if differently from an adult or a teenager. But it doesn't mean that it exist a single evolutive period to experience "now and forever" the satisfaction of specific needs. In disease progression, many studies [3,4,9,12,17] underline that "contact" is one of the main experience in caring needs satisfaction.

Life experiences making develop *directions* possible, so that they satisfy needs as above, are called Self Basic Experiences (EBS). If these experiences are adequately and often lived, thanks to a relationship with the environment, a better progressive satisfaction of specific needs is possible (*Ability* to interact with others and reality). EBS, if fully lived, can bring to emotional steadiness, resilience and flexibility to deal with life. They are called *life skills* and they help to face life events in a positive and healthy way (healthy as synonym of well-functioning, not as lack of disease, difficulties or suffering). Being *well-functioning* means, i.e., feeling able to close yourself off for a bad event and quickly re-open when the event is over; feeling anger when something is wrong and then remove it and bring back to calm and peace of mind; feeling pain when a

danger is on and rapidly bring back to calm when it is over. So, Wellness is feeling to possess personal resources to face negative and painful events of life, to not surrender to them, losing the ability to rejoice and enjoy life [63].

In Functional Psychology, in the *Self*-system of a cancer patient we can find an adaptive mobilization of *Fundamental Functionings*, with the aim to face emergency. Notably, *Planning*; *Sensations*; *Positive continuity* (memories, positive expectations); *Letting go* (abandon, daydream), *trusting*; *Control* (ability to concentrate); *Tenderness* (softness), the *Need of others* (fragility); *Being considered* (listened and understood); *Calm, ability to wait* (patience), *steadiness*; *Vitality* (activation, energy, enthusiasm); *Strength* (to face, to confront); *Resolution* (tenacity, going right to the end), *choosing* (decide) (Table 1).

Difficulties, coming from the environment, to live these Experiences make difficult, sometimes impossible, the satisfaction of needs. In medical environment, every physician deals with the conflicting needs of his job and queries on his abilities; sometimes, we can notice a swinging from a wish to getting close, to being involved in a therapeutical relationship and, in other moments and/or with different patients, a tendency to avoid a relationship, hiding behind “technicality”. Risks of misunderstanding, of conflict among medical people, are crucial and can bring to stiffening, distance and symptoms of *burn-out syndrome*, typify by inattention to communication, to painful symptomatology of the patient, to escape and indifference to the manifestations of nervous break-down of the patient and his family [3,4]. Specifically, many oncologists refer that, in caring, they are very often prevented by structural and management limits of the hospital [67]; this threatening satisfaction in caring from the patient’s point of view and in working wellness from the physician, who experiences a risk of burn-out. There are different models [68, 69] proposed during trainings to give to oncologists more means of communication, but a risk to dedicate more time to techniques instead of a deep contact with the patient is present [3,4,63,64].

Table 1 “*Self Basic Experiences*” (Rispoli L, 2011)

<p>HOLD Being hold contained stopped Being taken Being brought guided Protection</p> <p>CONSIDERED Being sees listened understood Being promoted appreciated</p> <p>LEAVE Leave lose being enchanted Trust rely to trust Abandon to other</p> <p>CONTACT Contact closeness fusion empathy</p> <p>RECEPTIVE CONTACT Being feed receive absorb Ask to receive to call</p> <p>ACTIVE CONTACT Take seduce take other Keep the other Change the other move transform Give hug donate</p> <p>VITALITY Joy jerk jump Vitality activate energy passion Play humour Dare go beyond</p> <p>CREATIVITY Creativity imagination Sense of beauty</p> <p>LIKE Like Excitement enjoy things Desire Like another person take pleasure from the other Wellness armony wholeness downward vagotonia</p> <p>ACHIEVEMENT Assertiveness affirm his own ideas Determination perseverance going to the end Choose decide</p> <p>SELF-ACHIEVEMENT Self-achievement Project to make dreams come true Success satisfaction Compete wish to win</p>	<p>CALM Calm serenity Wait patience Stay laze</p> <p>CONTROL Concentrate attention Smooth attention Lose control lose yourself holes explosions transgress breaks</p> <p>SENSATIONS Sensations feel know Perceive perceive reality, the other explore Wonder amazement</p> <p>LOVE Being loved kept inside Love keep inside give belong to other Positive continuity rmemories positive expectation Love yourself give yourself like self- comfort set</p> <p>TENDERNESS Tenderness sweetness smoothness Give up accept tolerate Necessity of the other</p> <p>CONDIVISION Open speak about yourself Share be interested exchange Alliance the other on your side Pleasure to the other show himself improve for the other</p> <p>STRENGHT Originary strength separate being noticed Smooth strength Calm strength face front power Open strength throw away</p> <p>AGGRESSION Tender aggression play Aggression to attack, to self-protect</p> <p>CONSISTENCE Presence exposure expand Consistence being worth certainty pride give self-value</p> <p>NEGATIVITY Rage Hate cruelty</p> <p>AUTONOMY Oppose deny Separate detachment Autonomy feeling good alone, independence</p>
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When the context, i.e. the environment where a person live (family, work, caring people), is not aware of the deep needs of protection, help and support of the oncological patient, the risk is that, with the aim to face disease, the patient become tough, using more and more a *Strength to resist* rather than a *Calm Strength*, an *Open Strength*. A *Calm Strength* allows to affirm his own point of view, an *Open Strength* allows to move people and contests in the aimed direction. When you say to a cancer patient, especially if a woman (women are often trained to use strength to resist), that he/she must be strong, you risk to implement a strength to resist. You raise a closure that helps not to feel pain and rage, with the risk that they may suddenly and unexpectedly explode (fantasies of death, self-underestimation, break and abandonment of important people) or implode with new symptoms and/or physical and psychological diseases (sleeping sickness, anguish, headaches, rashes, urinal disorders without infection, gastric disorders). All above allows us to consider disease both from a psycho-somatic and somato-psychic point of view, which means the entire organism [61,62].

Nowadays, in the perspective of complexity, thanks to interdisciplinary research and neuroscience discoveries, we have a lot of information about close and complex relationships between body and mind and we can abandon incomplete and dualist visions coming from the last century. The dichotomy mind/body, with a mind who rules and a body who execute, in a hierarchical supremacy of mind on body-soma, is exceeded by modern neurobiological knowledge. Our thoughts, our emotions, our memories, our fantasies have a base in the body, just like movements, breath, posture evocate emotions, thoughts, memories in a communion of psycho-corporeal processes who separate and are not congruent only when alterations are on.

Modern scientific knowledge support a vision of the person as an open complex system, able to face and adapt to the environment and, above all, to *self-manage*, i.e. to be managed by his/her own processes [70].

The functioning of a human being is carried out on different fields or levels, who are deeply integrated since birth. Functional Psychology – teorical and empirical background of the present work – reiterate and clarify a close and equal

connection between different systems (psycho-physiological, neurological, sense-motor, emotional and endocinous) who form the *Self*, defined as **integrated systems** [63]. The vision of the human organism as an open complex system, able to face and adapt to every event, allows us to consider “wellness” as the ability of *Self* to organize in a congruent and functioning way towards life events, both pleasant or unpleasant.

Many works [9,10,12,15,17,27] have explored needs in oncological patients, even if aware of his qualitative nature, badly fitting to quantitative measurements and metrical statistics. The need to better know some aspects of the disease such as, i.e., the specificity of the experience faced by the patient, the meaning of disease in the personal history of a patient, psycho-emotional characteristics of the healing process and the role of interpersonal support, has underlined that qualitative techniques can be an elective methodology [3,4]. This opinion suggests again that research has to be an instrument of clinics. Research means and methods have to shape themselves on the data of clinics, without reducing the complexity of the observed person and phenomenons [71].

Aims of the thesis

The aim of this work is exploring oncological patient’s needs in disease progression, considering relations with some specific factors of disease perception and quality of life. Moreover, we propose to enlighten some differences between patients from II line and IV line of treatment. The choice of the target is due to the wish to examine needs in “disease progression”, which is a less examined phase of the oncological disease in psycho-oncology, even if it faces the disappointment coming from a therapeutic failure and brings to important consequences on therapeutical alliance and on compliance. Our hypothesis are:

H1. The satisfaction of needs will be associated to a positive illness perception and a good quality of life; differently, the unsatisfaction of needs (unmet needs) will be associated to a negative illness perception and a bad quality of life.

H2. We imagine significant relationships among variables observed in the sample, considering these specific factors :

H2a. Negative emotional representations will be associated to a bad emotional functioning and to more unsatisfied needs;

H2b. A bad emotional functioning will be associated to high levels in symptomatic scales;

H2c. Unsatisfied needs in support and relational areas will be associated to high levels in symptomatic scales;

H3. Patients in II line of treatment will have more needs of information compared with patients in IV line and higher scores in cognitive functioning.

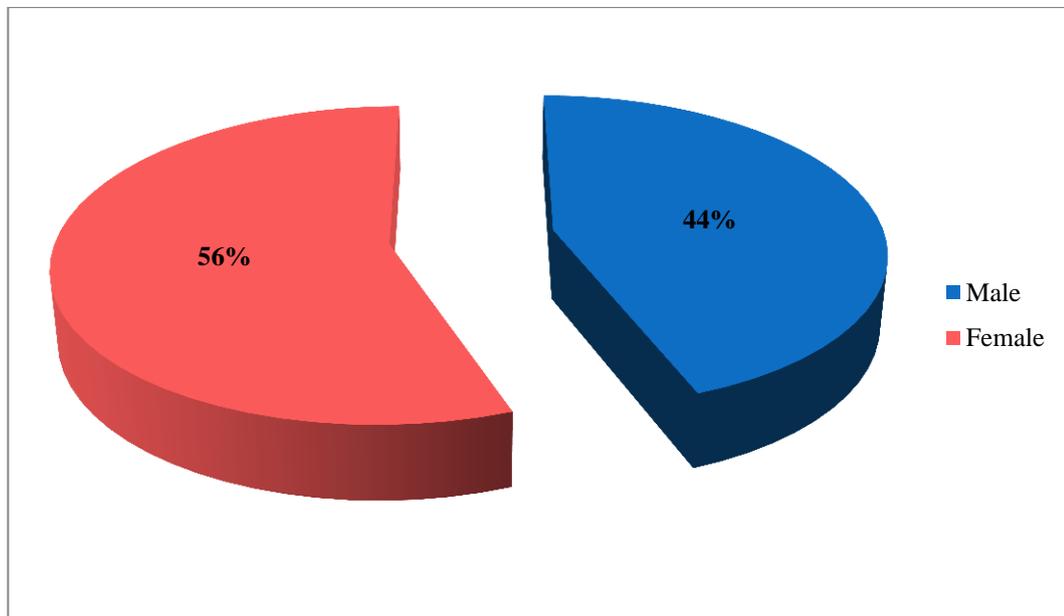
Analyzed factors are:

- Specific needs in prognosis information, treatment information, communication, assistance, structure, financial aspects, support and relationships areas;
- Cognitive Representations, Emotional Representations and Comprehension of the disease, who all together define Illness Perception;
- Functional scales and Symptom scales, who together define Quality of life (QoL).

Materials and Methods

This work has examined 61 oncological patients in disease progression (M=44%, F=56%), (Table 2) in treatment at H.U. of Medical Oncology of Policlinico in Palermo. Every interviewed patient has been included in the sample only once, even if it was possible, for the same patient, evaluate his/her progression many times during the treatment.

Table 2.



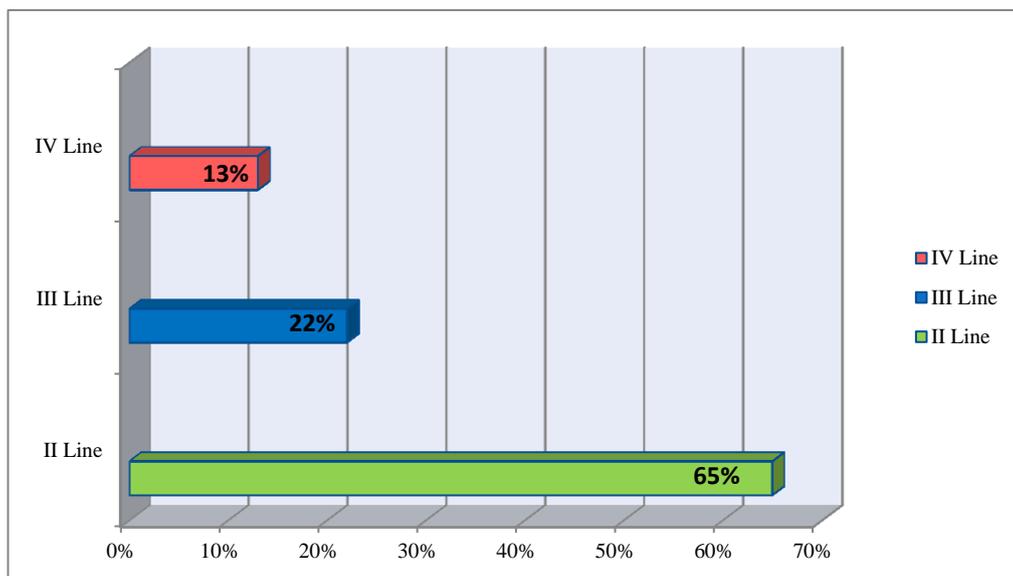
Age range from 47 to 88 years (M=66.57, SD=9.37). Almost of the subjects (73%) are married, while 10% are unmarried, 14% widower and widow and only 4% are divorced. There are no graduated subjects, most of the sample (61%) has primary school, while 25% completed junior high school and 11% high school. Employed subjects in the sample are barely 20%, housewife are 47% and pensioners 33% (Table 3).

Interviewed patients are all in situation of progression disease, but at different lines of treatment. In particular, 65% of patients are in line II, 22% is in line III and 13% is in line IV of treatment (Table 4).

Table 3. Sociodemographic characteristics of patients (N=61).

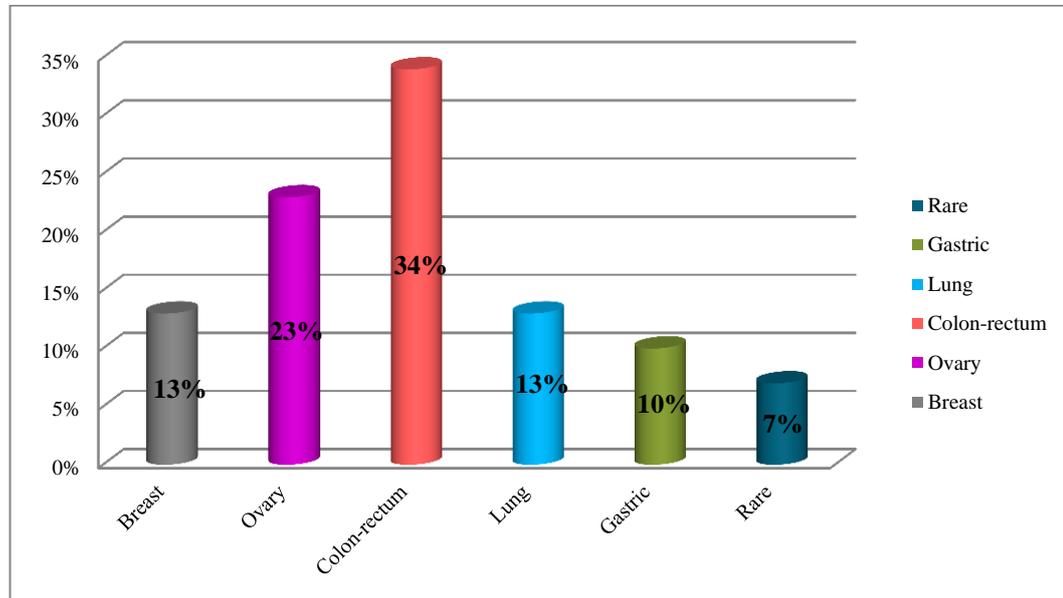
Patients (N=61)	
M (SD)	
Age (years)	66,57 (9.37)
Marital status	<i>f</i> (%)
Married	73%
Unmarried	10%
Widower/widow	14%
Divorced	3%
Level of education	<i>f</i> (%)
Primary school	61%
Junior high school	28%
High school	11%
Graduated	-
Employment status	<i>f</i> (%)
Employed	20%
Housewife	47%
Pensioners	33%

Table 4. Lines of treatment



Primary tumor site considered in our research are 13% breast, 23% ovary, 34% colon-rectum, 13% lung, 10% gastric and finally 7% rare (Table 5).

Table 5. Primary tumor site



Descriptive statistics were used to analyze the data. The subjects filled out self-report questionnaires designed to measure specific needs (Need Evaluation Questionnaire – NEQ), illness perception (Brief Illness Perception Questionnaire – Brief IPQ), and quality of life (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). Questionnaires were administered after therapeutic switch caused by chemotherapeutic treatment failure, so that patients could be followed in this delicate phase of treatment and supported to express their needs. At the same time, it has been proposed to them to participate to the present research, explaining aims and going on after informed consent.

Items administered were divided into four parts. The first part explores needs expressed in cancer progression, considering the following areas: prognosis information, treatment information, communication, assistance, structure, financial aspects, support and relationships. The second part analyzes cognitive representations, emotional representations and disease comprehension, who all

together define illness perception, which is the organized pattern of beliefs a patient develops during his/her medical condition [72]. The third part explores the quality of life in its bio-psycho-social components. The fourth and last part puts together personal information and informed consent. With the aim of analyzing specific areas, the following scales were used:

Needs

The Need Evaluation Questionnaire (NEQ) is a standardized questionnaire, consisting of 23 items, developed and validated at the Psychology Unit of INT [73]. This modality of needs collection acknowledges the central position of the patient with respect to his condition of disease and aims to increase the patient's opportunities to express his own requirements and his own discomfort. It asks about different types of needs: information concerning diagnosis/prognosis (2 items), information concerning exams and treatment (2 items), communicative (4 items), and relational (3 items), which make up four distinct factors; twelve further single item scales related to assistance and treatment (5 items), to structure (1 item), to financial aspects (2 items) and to support (4 items) complete the questionnaire. The subjects were asked to indicate their unmet needs using a unidimensional scale (Yes or No), that reveals the presence/absence of differential needs. It has been chosen a simpler “yes” vs. “no” response scale because when the authors asking patients to graduate their needs on a four-point verbal Likert scale (not at all/a little/much/very much), many of them indicated a difficulty in graduating the level of their needs. This choice is consistent with the aim of our research, which is not to attribute a global point system to the patients' need state, rather than the presence/absence of differential needs, which will then be closely examined within the context of the clinical relationship for obtaining operative and adequate responses.

Illness perceptions

The Brief Illness Perception Questionnaire (Brief IPQ) is a 9-item questionnaire designed to rapidly assess cognitive and emotional representations of illness [74]. The Brief IPQ uses a single-item scale approach to assess perception on a 0–10

response scale. It is developed by forming one question that best summarizes the items contained in each subscale of the Illness Perception Questionnaire-Revised which has over 80 items. The cognitive and emotional representations of the illness, or illness perceptions, determine the individual's coping behaviour [74]. Five dimensions within the cognitive representation of illness are identified: identity – the label the individual uses to describe the illness and the symptoms they view as part of the disease; consequences – the expected effects and outcome of the illness; cause – personal ideas about the cause of the illness; timeline – how long the individual believes the illness will last; and cure or control – the extent to which the individual believes that they can recover from or control the illness. The emotional representation (2 items) incorporates negative reactions such as fear, anger, and distress. One item is on illness comprehensibility. The last item is on perceived cause of illness, in which respondents list the three most important causal factors in their illness. The main advantages offered by the Brief IPQ to researchers are brevity and speed of completion for patients, as well as the easy interpretation of scores: increases in item scores represent linear increases in the dimension measured.

Quality of life

The EORTC quality of life questionnaire (QLQ) is an integrated system for assessing the health – related quality of life (QoL) of cancer patients [75]. In the last years, the QLQ-C30 has been used in a wide range of cancer clinical trials, by a large number of research groups; it has additionally been used in various other, non-trial studies. Version 3.0 is currently the standard version of the QLQ-C30. The content areas covered by the questionnaire reflect the multi-dimensionality of the QoL construct. The QLQ-C30 is composed of both multi-item scales and single-item measures. There are five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), a global health status/QoL scale, and six single items (dyspnea, loss of appetite, insomnia, constipation, diarrhea and perceived financial impact of the disease). Each of the multi-item scales includes a different set of items; no item occurs in more than one scale. All of the scales and single-item measures range in

score from 0 to 100. A high scale score represents a higher response level. Thus a high score for a functional scale represents a high/healthy level of functioning, a high score for the global health status/QoL represents a high QoL, but a high score for a symptom scale/item represents a high level of symptomatology/problems.

Results

Descriptive statistics were used to analyze data, with the aim to enlighten variety and abundance of meaning that answers to questionnaires had in every patient's personal experience. This kind of sample concentrate more on the identification of richest (of information) cases than on representativeness [76,80]. High quality exploratory research is fundamental to follow clinical practice [77,80]. As needs never appear alone, but in a complex net of interactions in which they are consequently linked, "needs interrelations", especially when observed in a context of perspectival studies and different moments of the disease, can be used to predict and potentially improve needs evaluation [31,78,79,80]. The aim of this work is not generalize results, but explore and support a patient's complex experience, by associating expressed needs and different dimensions of disease perception and quality of life.

Needs observed by NEQ were put together in different areas. In detail: *diagnosis/prognosis information*; *exams/treatment information*; *communication*, who mainly concerns relationships with physicians (feeling of being – or not – in a honest and encouraging relationship, based on dialogue); *relationships*, who concerns a patient's perception of his/her role in a wide context (family, other patients, society); *assistance and treatment*, who concerns medical/nursing aid and symptoms control; *structure*, i.e. services offered by the hospital; *financial aspects*, who concerns economical support and tax breaks; *support*, who also

includes psychological and spiritual aspects. Exploration of needs was measured by the distribution of percentage frequencies coming from positive answers and from missing values in every area of the questionnaire (Table 6).

Table 6. NEQ percentage frequency of positive answers and missing values for each area (N = 61)

Item numbers	Areas	% of Yes	% of missing data
1,2	Diagnosis/prognosis Information	21	1
3,4	Exams/treatment Information	20	1
5 to 8	Communication	31	0
20 to 22	Relationships	84	0
9 to 13	Assistance and treatment	66	0
14	Structure	17	1
15,16	Financial aspects	14	2
17,18,19,23	Support	64	0

Percentages of missing values in every area are very low (range 0-2%), so it indicates a good understanding and acceptability of the questionnaire by interviewed people. More expressed needs are in the areas of relationships (84%), assistance (66%), support (64%) and communication (31%).

Information on diagnosis/prognosis and exams/treatment remain under 25%, enlightening a huge contrast between the progression disease phase (considered in this work) and the diagnostic phase (considered in many works in literature) where, instead, there is a great need of information.

The less expressed need is about financial field (14%), because of subventions and tax exemptions for oncological patients from National Health Service. At last, only 17% of expressed needs concerns medical centers and services provided; they seem to work well.

In addition to exploring needs, we examined cognitive representations, emotional representations and the general comprehension of the disease, who all together form the illness perception, that is an organized pattern a patient develops about

his/her own condition of “ill”. The cognitive representation of the disease (RC) includes:

- identity – the tag a patient use to describe illness and symptoms considered as part of the disease;
- consequences – expected effects and disease's outcome;
- causes – personal ideas about that causes of the disease;
- timeline – how long the disease will last, in patient’s opinion;
- care or check – how likely a patient think he/she can get better or control the disease.

The emotional representation of the disease (RE) is made up, instead, of negative reactions like fear, rage and anguish. At last, comprehension (C) concerning the understanding of the disease.

Generally, negative perceptions of the disease are linked to poor recovery and higher resort to Health Service, independently of the real seriousness of the disease; whereas positive perceptions of the disease are associated to a better recovery and a shorter timeline [74].

Within the examined sample, we observed that patients satisfied about the area of *assistance* (evaluated in NEQ) has a positive perception of the disease, too. It may reasonably be supposed that the therapeutical relationship (which is part of the *assistance*) influences the disease’s perception, which is positive when patients feel confident of the doctor. The need to *be guided* is the most reported by our patients. In their condition of weakness, the main mean of the therapeutical alliance is being guided by a physician.

Among interviewed patients, moreover, those who have a positive perception of the disease report a good quality of life, too. The disease’s perception is negative in 32% of the sample, positive in 68%. If we observe perception’s data and we cross-check them with socio-demographic data, we can observe that younger patients (age range from 47 to 88 years) in II and III lines of treatments have a negative perception of the disease and report an higher impact on daily routine, with consequences on self-perception in relationships and social roles (low scores

in Social functioning scale of EORT QLQ-C30). It's interesting to underline that those patients had obtained good scores in comprehension (C) and in the sub-element called *control* of cognitive representations (RC). This postulate indicates that, even within a negative perception, those patients maintain hope and belief in recovery and/or disease's control. A good comprehension (C) is linked, moreover, to higher education owned especially by younger patients. Emotional representations (RE) in this section of the sample reach low scores (difficulty to express negative feelings as anxiety, fear and anguish), consistent with bad emotional functioning within *quality of life* (Emotional functioning scale of EORT QLQ-C30).

Older patients (age >75 years old) in III and IV lines, in comparison with younger patients, have higher scores in emotional representations (RE), but associated to depression percentages observed in emotional functioning of quality of life (Emotional functioning scale of EORT QLQ-C30). Those patients show, moreover, bad opening in familiar and friend relationships (low scores in Social functioning scale of EORT QLQ-C30) and total commitment to the physician in therapeutical choices. This last assumption is linked to low percentage of expressed needs about information (<25%) (Table 6) and can be explained if we consider the influence of the sicilian cultural context, full of heritage from past dominations who made "being guided" a fundamental need for surviving. Another assumption about low rates about information could be low education of older patients.

Considering, at last, in the observed sample, quality of life, a global health status (QoL of EORT QLQ-C30) is linked to the satisfaction of needs and a positive illness perception. 78% of interviewed patients report a fair or good quality of life. This assumption can be explained also by the presence of a partner (73% of the sample is married) to share practical difficulties with and by the fact the patient mustn't be out (of home) for a long time (only 20% has a job outside from home).

The low score in emotional functioning in younger patients in II and III lines of treatment – linked to low scores in RE of illness perception – can be explained, from a psychological point of view, by the refusal of a deep contact with his/her

own feelings that, in the target examined, are often anguish of death, fear to leave relatives, sense of defeat and helplessness.

Those emotional status, often not shared for fear to hurt him/herself or other, are shown by physical symptoms as panic attacks and insomnia. This former – evaluated by single-item Insomnia of EORT QLQ-C30 – is reported by almost all interviewed sample (87%). It is interesting to underline that patients had less difficulty to report physical symptoms like insomnia (that is inability to let thoughts and worries) but not fears.

Respect to the variable Primary tumor site, important differences in expressing needs or quality of life's data are not recorded.

Discussion

The results of the present work confirm some of our hypothesis. **H1** supposed an association between satisfaction of needs, positive illness perception and a good quality of life. **H1** also supposed that unmet needs are associated to a negative illness perception and a bad quality of life. Within the sample, a good amount of needs (Diagnosis/prognosis Information, Exams/treatment Information, Structure, Financial aspects) is satisfied, illness perception is positive in 68% and quality of life is reported as good or fair in 78% of patients. An association between unmet needs, negative illness perception and fair quality of life was not found, instead. For that reason, our first hypothesis was only partly confirmed.

In **H2a**, we supposed an association between negative emotional representations (RE), fair emotional functioning (Emotional functioning scale) and more unmet needs. Among interviewed patients, we observed an association between negative emotional representations and fair emotional functioning, both linked to a difficulty to express negative feelings like anxiety, fear, anguish; moreover,

patients with negative emotional representations and fair emotional functioning reported a higher amount of unmet needs in different examined areas; so our hypothesis is confirmed.

H2b supposed an association between a fair emotional functioning and high scores in symptomatic scales. The only symptomatic scale who obtained high scores is the single-item Insomnia of EORT QLQ-C30, showing insomnia in almost the total amount of the sample (87%). However, this symptom is reported in patients with a good emotional functioning, too, so that we can suppose a general difficulty within the sample to leave thoughts and worries linked to disease. So, our hypothesis is not confirmed.

H2c supposed an association between unmet needs in *support* and *relationships* areas and high scores in symptomatic scales. This hypothesis is not confirmed, because we did not observe a high symptomatology, but only insomnia. Other symptoms observed are well controlled within the sample.

H3 supposed the presence of higher scores in cognitive functioning and in information needs of patients in II line than patients in IV line of treatment. We did not find important differences between information needs of patients in II line than in IV line patients. We observed, instead, higher scores in cognitive functioning in patients in line II. This data could be explained by a higher “control” (higher attention or alert) in patients receiving the bad news of disease progression for the first time than patients who have changed many treatments. Therefore, this hypothesis is only partly confirmed.

Unmet needs were observed in relationships, support, assistance and communication areas. Referring to Functional Psychology, theoretical and empiric background of the present work, we can observe “basic experiences” (Table 1) patients have to undergo to satisfy expressed needs during the treatment.

Needs in relationships area concerns the perception a patient has of his/her own position in family and society; the basic experience a patient has to undergo to satisfy needs in relationships is *Being considered*, which is being seen in

difficulties, heard in what you need to say, understood in the way of thinking about his/her own illness condition.

Needs in support area – concerning, extensively, also psychological and spiritual aspects – can be satisfied by experiences of *Contact* and *Need of the other*: contact is a very deep experience of closeness to the other, in a sense, fusion, empathy, something allowing us to incorporate feelings and emotions from another person; the need of the other, instead, is to admit our fragility and give a positive value to it, because the help from others is an essential condition to surviving and is not only linked to disease.

To satisfy needs in the area of assistance - i.e. medical/nursing assistance and symptoms control - the experience of *Being hold* (with its different shades) is crucial. So, in clinical practice, it happens that physicians and medical staff have to “hold” a patient, giving back to him calm and serenity; “guide” a patient during his/her complex and critic therapeutical path; “protect” a patient, for example from overabundance of information and bad news, making him to be confident in caring staff.

Satisfying needs in the area of communication – mainly concerning physicians, the feeling of being (or not) in an authentic, comforting, dialogue-based relationship – means allowing a patient to undergo the experience of *Leaving*, losing control, thoughts and worries to totally trust in physician, experiencing trust and confidence. Finally, one of the most important experience of the entire treatment is *Condivision*, which is possible thanks to opening to others and ability to talk about something and/or him/herself.

Conclusions

All human beings have fundamental needs to be respected and satisfied lifelong. Exploring a patient's needs in disease progression allow us to have clear data on how "satisfy" them, on what "basic experiences" [63] make patients undergo to preserve their quality of life and obtain the specific therapeutical alliance that gives a valuable asset to care, leaving aside healing.

Data show some conclusions. In general, more expressed needs are in the areas of relationships, support, assistance and communication. In detail, those needs are fundamental ones linked to the whole life. In a condition of deep fragility, just like disease progression, a patient need to be considered, seen and heard; he/she has to be able to experience a deep contact and the need of the other as a positive value; he/she has to be held, contained, guided and protected from the caring équipe; he/she needs to abandon to the physician, experiencing trust and confidence; he/she needs to share his/her life without thinking of fearing or stressing the other (this means speaking about death, too, without exorcisms and fake reassurances).

If these needs are found and satisfied, they can be reasonably considered to predict a good quality of life. In fact, it has been observed an association between satisfaction of needs, positive illness perception and good quality of life.

In literature, different studies have been done on how to receive patients' needs and there are different patterns to improve physicians ability to communicate, with the aim of facing caring needs. Together with these studies, we also consider to do explorative studies [80] having, as main instruments, observation and clinics, to establish a contact between clinics and research, so important in complexity eve [71], where a patient's needs change rapidly.

A limit of the present work is that it is impossible to generalize from a so little and specific sample (i.e. with very specific socio-demographical characteristics). The limited sample is due to the chosen target that, being made up of oncological patients in disease progression, narrows our field of observation. However, further

studies could use a wider sample, more representative of the general population, and extend the analysis. Another limit of this study is the exclusive study of self-report questionnaires. Objective data would be more reliable.

However, the choice of instruments was made following criteria of clarity and shortness of questionnaires, so that they could be proposed to less educated or serious ill patients, too. Results are showed taking into account the descriptive value of data; their richness was analyzed considering interrelations among needs, seen in progression disease.

Anyway, in spite of its limits, this study contribute to explore and support complexity and richness in patients' experience, by associating expressed needs and different dimensions of illness perception and quality of life.

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Table 1 “*Esperienze Basilari del Sé*” (Rispoli L, 2011)

<p>TENUTI Essere Tenuti contenuti fermati Essere Presi Essere Portati guidati Protezione</p> <p>CONSIDERATI Essere Visti ascoltati capiti Essere Valorizzati apprezzati</p> <p>LASCIARE Lasciare allentare incantarsi Fidarsi affidarsi fiducia Abbandonarsi all'altro</p> <p>CONTATTO Contatto vicinanza fusione empatia</p> <p>CONTATTO RICETTIVO Essere nutriti ricevere assorbire Chiedere per ricevere richiamare</p> <p>CONTATTO ATTIVO Prendere sedurre portarsi l'altro Tenersi l'altro Cambiare l'altro muovere trasformare Dare abbracciare regalare</p> <p>VITALITÀ Gioia guizzi slancio Vitalità attivarsi energia passione Giocare umorismo Osare andare oltre</p> <p>CREATIVITÀ Creatività immaginazione Gusto del bello</p> <p>PIACERE Piacere eccitazione godersi le cose Desiderare Piacere dell'altro trarre piacere dall'altro Benessere armonia interezza verso il basso vagotonia</p> <p>AFFERMAZIONE Assertività affermazione delle proprie idee imporsi Determinazione tenacia andare in fondo Scegliere decidere</p> <p>AUTOAFFERMAZIONE Autoaffermazione Progettare per concretizzare sogni Realizzazione soddisfazione Competere voler vincere</p>	<p>CALMA Calma tranquillità Aspettare pazienza Stare oziare</p> <p>CONTROLLO Concentrarsi attenzione Attenzione morbida Allentare controllo sciogliersi Perdere controllo buchi esplosioni trasgredire crolli</p> <p>SENSAZIONI Sensazioni sentirsi conoscersi Percepire percepire l'altro, la realtà esplorare Stupore meraviglia</p> <p>AMORE Essere amati portati dentro Amare portare dentro darsi appartenere all'altro Continuità positiva ricordi aspettativa positiva Amarsi dare a sé piacersi autoconsolarsi sistemarsi</p> <p>TENEREZZA Tenerrezza dolcezza morbidezza Cedere accettare tollerare Necessità dell'altro fragilità</p> <p>CONDIVISIONE Aprirsi raccontare di sé Condividere cointeressarsi scambiare Alleanza l'altro dalla propria parte Piacere all'altro mostrarsi migliorarsi per l'altro</p> <p>FORZA Forza originaria distaccarsi farsi spazio Forza morbida Forza calma affrontare fronteggiare potenza Forza aperta buttare via</p> <p>AGGRESSIONE Aggressione affettuosa giocosa Aggressione per difendersi attaccare</p> <p>CONSISTENZA Presenza visibilità espandersi Consistenza avere peso sicurezza fierezza valorizzarsi</p> <p>NEGATIVITÀ Rabbia Odio cattiveria</p> <p>AUTONOMIA Opporsi rifiuto Separarsi distacco Autonomia stare bene da soli non dipendenza</p>
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Exploratory study about disease progression cancer patients needs

Battiato S., Cicero G., De Luca R., Bronte G., Russo A.

Background. Oncological disease progression can become difficult to manage for the physician, for the aspects to concern therapeutic switch after previous treatments' failure, but also for patient reassurance needs that oncologist have to be linked with information about clinical conditions. Theoretical and empirical basis refer to neo-functionalism in psychology. Neo-functionalism consider person an integrated system, an organization of functions (rationality, memories, fantasies, emotions but also movements, postures and physiological systems). Neo-functionalism looks at fundamental needs of patients.

Purpose. This study aims to investigate emotional experience and psychological needs of cancer patients, who have experienced disease progression and are actually in treatment at Department of Surgical, Oncological and Oral Sciences, University of Palermo. We believe that a greater knowledge about patient's specific needs of information, involvement, distress and perceived quality of life, may facilitate care relationship in disease progression conditions.

Methods. Patients who are progressed after a chemotherapy have undergone to psychological tests (Brief Illness Perception Questionnaire – Brief IPQ; EORT QLQ-C30; Needs Evaluation Questionnaire – NEQ); clinical interview showed the multiplicity and richness of meaning that the affirmations of psychological tests had in the subjective world of the individual patient. Also socio-demographic data and informations on medical therapies are considered.

Results. During their interview, patients give greater importance to the empathic relationship with physician rather than accurate information about disease. A good emotional contact reduces fear and increases trust, so physician can guide patients also in difficult step such as therapeutic switch after a previous treatments' failure. Patients prefer that physician makes treatment decisions rather than to participate actively in decisions. The fragility in progression disease is accompanied by low illness control perceived, and greater delegation to the physician. The last result may be influenced by Sicilian cultural context, characterized by great caregiving and ability to be guided. Moreover, delegation to the physician is higher in patients with low levels of education.