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Patient reported areas in psychooncological counseling

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Abstract

Objective: We proposed to investigate the areas in psychooncological counseling that patients reported as causing the most distress, as well as the level of emotional distress cancer inflicts and its relation to idiosyncratic variables. **Method:** A sample of fifty-one patients from Porto's IPO responded to a socio-demographic and clinical questionnaire, to the CORE-10, to the Distress Thermometer, and to an idiographic measure, the Simplified Personal Questionnaire (PQ). The therapists completed a questionnaire regarding their adherence to the PQ protocol. The data analysis consisted of assessing the patients' emotional distress and thematically analyzing the PQ. **Results:** The patients showed a high level of emotional distress regarding the problems described in the PQ. The main areas of issues patients indicated were Life Functioning, Anxiety and Depression. **Conclusions:** The psychosocial implications of the disease in the day-to-day functioning were the main area identified as a priority for counseling, which attests to the importance of focusing initial oncological counseling on helping patients overcome their limitations.

Key-Words: Cancer, Simplified Personal Questionnaire (PQ), Distress, Screening, Counseling

Resumo

Áreas de aconselhamento psicooncológico reportadas por pacientes

Objetivo: Propusemo-nos investigar as áreas de aconselhamento psicooncológico que os pacientes reportam como causadoras de maior sofrimento, bem como o nível de sofrimento emocional causado pelo cancro e a sua relação com variáveis idiossincráticas. **Método:** Uma amostra de cinquenta e um pacientes do IPO do Porto responderam a um questionário sociodemográfico e clínico, ao CORE-10, ao Termómetro de Sofrimento Emocional, e a uma medida ideográfica, o *Simplified Personal Questionnaire* (PQ). As terapeutas completaram um questionário de adesão ao protocolo do PQ. A análise dos dados consistiu na avaliação do sofrimento emocional dos pacientes e na análise temática do PQ. **Resultados:** Os pacientes apresentaram um alto nível de sofrimento emocional relativamente aos problemas descritos no PQ. As principais áreas de apoio indicadas pelos pacientes foram Funcionamento Vital, Ansiedade e Depressão. **Conclusões:** As implicações psicossociais da doença no dia-a-dia foi a principal área identificada como uma prioridade para o aconselhamento, o que atesta a importância de focar o aconselhamento oncológico inicial em ajudar os pacientes a superar as suas limitações.

Palavras Chave: Cancro, *Simplified Personal Questionnaire* (PQ), Sofrimento Emocional, Triagem, Aconselhamento.

Contents

Introduction.....	9
I - Theoretical Framework	12
1. Introduction to Cancer	13
1.1. Definition.....	13
1.2. Development Stages	13
1.3. Treatment	14
2. The Psychosocial Implications of Cancer.....	16
3. Psychological Impact of Distress in Cancer Patients	17
4. Psychological Counseling in Cancer Patients	19
5. Objectives and study rational	21
II - Method.....	23
1. Participants	24
2. Instruments	26
2.1. Socio-demographic and Clinical Questionnaire	26
2.2. 10-item Clinical Outcomes in Routine Evaluation questionnaire (CORE-10) ..	26
2.3. Distress Thermometer (DT).....	26
2.4. Simplified Personal Questionnaire (PQ).....	26
2.5. Therapist's Adherence to PQ Protocol Questionnaire.....	27
3. Procedure.....	28
3.1. Data collection	28
3.2. Data analysis	29
III - Results	31
1. Quality of PQ items and Adherence to PQ protocol	32
2. Emotional state of oncological patients.....	33
3. Problems and priorities of oncological patients	33
4. Patients' emotional distress related to personal and disease variables	37
IV - Discussion.....	42
V - References.....	46
ANNEX	57
Annex 1: CORE-10	58
Annex 2: Personal Questionnaire.....	59
Annex 3: Distress Thermometer	63
Annex 4: Socio-demographic and Clinical Questionnaire	64
Annex 5: Therapist's Adherence to Protocol Questionnaire.....	65

List of Figures

Figure 1. The bio-neurological model for the impact of distress on cancer progression	18
Figure 2. Patient flow chart	28

List of Tables

Table 1. Patients' socio-demographic and clinical characteristics	24
Table 2. Item quality classification.....	32
Table 3. Therapists Self-Rated adherence to PQ protocol.....	32
Table 4. Patients' emotional state scoring.....	33
Table 5. Patients' problems and priorities by item & by patient.....	34
Table 6. Age related to psychological distress	37
Table 7. Gender related to psychological distress.....	37
Table 8. Previous treatments related to psychological distress	38
Table 9. Current treatments related to psychological distress	39
Table 10. Phase of treatment related to psychological distress.....	40
Table 11. Diagnosis related to psychological distress	41

Introduction

The impact of cancer is global and it not only takes a physical toll, it brings with it many psychosocial implications. This has been the focus of many studies before, however, the majority of these studies and analysis of the oncological population are made from the view point of health professionals and academics not taking into account the views of the patients themselves. This gap is precisely what this study proposes to fill by giving the patients who indeed suffer the implications of an oncological disease the chance to be heard and report the areas they feel should be addressed in psychooncological counseling. With this in mind we propose to define a baseline for psychooncological counseling, to assess the patients need for counseling, and to create patient profiles regarding their clinical and social-demographic characteristics. In order to achieve our propositions the study was conducted in a naturalistic manner in a psychooncological counseling unit where the patients psychological distress was analyzed and their counseling priorities were reported. In order to facilitate the analysis of the patients point of view we decided on an idiographic measure over regular interviews. The measure chosen was the Simplified Personal Questionnaire (PQ) (Elliott, Mack & Shapiro, 1999), which was also analyzed in regards to the feasibility of its regular usage in a psychooncological counseling context.

This study was organized according to the Strobe Statement for Cross Sectional Studies (von Elm et al., 2008). Beginning with a theoretical framework that portrays the condition affecting the patients and the various possibilities of treatment. Followed by the psychosocial implications of the disease and the psychological impact of distress in cancer patients. The relevance of psychological counseling for oncological patients is then addressed as well as a description of the various formats it can take. The theoretical framework comes to a close on the explanation of the purpose of the study and its importance as well as a clear definition of the objectives. The description of the study follows the theoretical framework, starting with the participants - two psychologists and fifty one patients - and the five instruments used - 10-item Clinical Outcomes in Routine Evaluation questionnaire; Simplified Personal Questionnaire; Distress Thermometer; Socio-demographic and Clinical Questionnaire; Therapist's Adherence to Protocol Questionnaire. Then the data's collection and analysis are explored. The analysis begins with the examination of the quality of the PQ items and the therapists adherence to the PQ protocol. Then the analysis focuses on the emotional state of the patients and afterward on the portrayal of the patients'

problems and priorities. The last stage of the analysis scrutinizes the relationship between the patients' emotional distress and, personal and disease related variables. After the study's description the results are presented and discussed.

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I - Theoretical Framework

1. Introduction to Cancer

1.1. Definition

Cancer is a generic term that represents a group of diseases whose main feature is the accelerated and uncontrolled growth and spread of cells that can affect any part of the body as well as invade the adjacent tissue and metastasize to distant locations. The process of metastasis is one of the prime causes of death from cancer (WHO, 2014).

Since the beginning of the 20th century cancer's incidence and mortality rates have been steadily increasing, making it one of the most severe threats to a healthy life. The number of people who were diagnosed with cancer and died of the disease reached 10.1 million and 6.2 million respectively in 2000 (Dong et al., 2002) and these figures increased to 10.86 and 6.73 million only two years later (Stewart et al., 2003). It is estimated that, by 2020, people living with cancer will add up to 30 million and annual new cases and deaths of the disease will rise to 15 million and 10 million (Parkin et al., 2005). Despite the steadily increasing mortality rates, the figures regarding survival have also improved. Since 1971's until 2011 the 5 year survival rate for all types of cancer in England and Wales grew on average 24.5% while the 1 year survival rate grew 20.4% and the 10 year survival rate grew 25.8%. When specifying the type of cancer some growths of the survival rates are staggering, for example the multiple myeloma survival rate more than tripled from 12.6% to 44.5% while for leukemia an low 11% survival rate grew to 55.6% (Quaresma, Coleman, & Rachet, 2015).

1.2. Development Stages

There are various stages of oncological disease that describe the extent or spread of cancer cells at the time of diagnosis, the most commonly used staging system refers to four stages (WHO, 2014):

- Stage 0 - in this stage cancers are still located in the place they started and have not invaded nearby tissues. This stage of cancer is often highly curable, usually by removing the entire tumor with surgery.

- Stage I - This is usually a small cancer or tumor that has not grown deeply into nearby tissues and has not spread to the lymph nodes or other parts of the body. It is often called early-stage cancer.

Stage II and III - These stages indicate cancers or tumors that are larger in size, have grown more deeply into nearby tissue, and have spread to lymph nodes, but not to other parts of the body

- Stage IV - This stage means that the cancer has spread to other organs or parts of the body. It may also be called advanced or metastatic cancer.

1.3. Treatment

The type of cancer treatment depends on the type, location, and stage of the cancer as well as the general health status of the patient. For any type of treatment patient consent is always required. The most common cancer treatments available are surgery, chemotherapy, and radiation therapy, but there are other types of treatment that can help patients battle the disease, such as hormone therapy - occasionally used to treat certain kinds of prostate and breast cancers - immunotherapy - intended to boost the cancer patient's own immune system to help fight the cancer - targeted therapy - targets the cancer cells and causes less damage to healthy cells - and stem cell or bone marrow transplants (Skeel & Khleif, 2011).

Cancer surgery may be the best chance of a treatment for many types of cancer, removing all of the cancerous cells as soon as possible after the diagnosis. Curative surgery, as it is called, is done when the cancer is found in only one part of the body, and the likelihood of total removal is high. Meaning that usually when the cancer is in Stage 0 or I the surgery will be most likely possible whereas in Stages II and III it may be more difficult to ensure that the removal of the cancer will be complete, and in Stage IV surgery is no longer an option. This type of treatment can be used by itself or in league with other treatments such as chemotherapy or radiation therapy, which can be given before or after the operation to shrink the cancerous cells and facilitate their removal or to eliminate the ones that could not be removed during the surgery (Rosenberg, 2011).

Radiation Therapy helps destroy the cancer cells by damaging the DNA within said cells, the normal cells may also be affected but have a higher ability to resist the radiation. This type of treatment is achieved, mainly, through irradiation where high-energy waves (x-rays, gamma-rays, electron beams, protons) are externally directed at the cancer cells but there is also the possibility of internal radiotherapy where a radioactive foreign object is placed inside the body near the tumor (Chao, Perez, & Brady, 2011).

Chemotherapy is a form of cancer treatment that uses chemical substances to treat the disease killing cells that rapidly divide, as cancer cells do. Chemo can be effective throughout the whole body whereas surgery, as well as radiation, can only

affect cancer cells in a determined area of the body. Hence, chemotherapy is the most effective type of treatment for Stage IV cancers because the cancer cells are metastasized to various parts of the body (Skeel & Khleif, 2011). There are well over 100 chemical substances that can be used for chemotherapy treatments. Alone chemo drug can be used to treat cancer, but it is more common that multiple drugs are selected to administer in a certain order or combination (combination chemotherapy) to have a better and faster effect. The usage of various types of chemotherapy drugs with diverse actions can work also reduce the chance of the cancer becoming resistant to any specific drug (in idem).

All these types of treatments are, of course, very violent for the whole body, not just the cancerous cells, and there are always side effects that surface after the patient is subjected them. The side effects of cancer surgery are no different than any other surgery, meaning that pain, small infections, bleeding, and a slower recovery of regular bodily functions are to be expected (Rosenberg, 2011). Commonly people who are subjected to radiotherapy present a variety of skin problems as the main side effect, such as itching, peeling, dryness, or blistering, but they also generally feel a persistent sense of exhaustion that does not improve after a long rest or with a decrease of physical activity (Chao, Perez, & Brady, 2011). In regards to chemotherapy, this being the most invasive type of treatment, the side effects are greater in number and severity, but may vary depending on the type of chemicals used, fatigue, like in radiotherapy, is a main side effect. Pain, general or specific such as muscular pain, stomach pain, or headaches is also a very common side effect of this type of treatment. Beyond these the patients also tend to experience nausea and vomiting, diarrhea/constipation, mouth and throat sores, appetite loss, hair loss, cognitive dysfunction, sexual and reproductive issues, or even blood disorders (Skeel & Khleif, 2011). However, not all side effects are as physical as these, there is always a psychological and cognitive aftermath to these treatments which will be explored in detail further on.

Another characteristic of cancer is the possibility of recurrence. Cancer may recur in four different ways: local recurrence - occurs in the same area -, regional recurrence - occurs in the lymph nodes near the previously treated area -, and distant recurrence - occurs at a remote location and is considered a metastasis of the original cancer. Cancer recurrence can occur due to several factors, many may be the variables that determine the probability of reoccurrence but the more prominent are tumor size, lymph node status, and type of cancer (Ricks, 2005).

After the detailed description of cancer and its impact, a broad description of cancers' development and its treatments becomes apparent, recognizing five distinctive phases: diagnosis - first confrontation with the disease -, advanced disease -

cancer stages 3 and 4 -, treatment - battling the disease in various ways -, survival - in complete remission for over five years after the treatment, and recurrence - the resurfacing of a previously battled cancer (Hewitt, Greenfield, & Stovall, 2006).

This is the affliction that ails our subjects, viewed from a medical standpoint, which not only carries many psychological and social implications but is also influenced by those same factors.

2. The Psychosocial Implications of Cancer

Associated with the great physical damages it causes, cancer inflicts an enormous psychological and social distress. Although the prevalence of psychological distress is dependent on the type of cancer, time since diagnosis, prognosis, and other variables, it can be estimated that 29 to 43 percent of cancer patients suffer from it significantly (Carlsen et al., 2005; Hegel et al., 2006; Mitchell et al., 2011; Spiegel & Giese-Davis, 2003; Zabora et al., 2001). Generally, cancer patients find themselves in an extreme fragile state after the diagnosis, for it represents an unexpected crisis in the patients' life cycle and may also bring about changes in the family's structure (Kornblith, 1998). Seeing as a cancer diagnosis is usually associated with a great amount of distress from a firsthand confrontation with death, a prospect of great pain and anguish possibly joined by a disbelief in remission, joined by feelings of guilt, a sense of loss of control, confusion, anger and sadness, also body image related concerns and family cohesion problems may emerge (Charmaz, 2000; Gregurek et al., 2010; Jacobsen et al., 2000; Kornblith, 1998; Stanton et al., 2001), all of which can be worked on in counseling. There is a type of distress adjacent to any confrontation with death, and a cancer diagnosis is no different, which is a confrontation with the patients' faith and spirituality as well as an adjustment of their perceived relationship with their deity (IOM & NRC, 2006). This distress is prolonged because it is present throughout the various stages of the disease and sometimes (approximately 30% of cancer patients) culminates in the development of psychopathology, namely anxiety and adjustment disorders and most commonly depression, meaning that the patients in fact need mental care (Akechi et al., 2001; Grassi et al., 2004; Kissane et al., 2004; Mitchell et al., 2011; Miovic & Block, 2007; Mystakidou et al., 2005). Although these are the psychological disorders that surface the most there is another which is of some import - Post-Traumatic Stress Disorder (PTSD). From what has been reported above and according to the DSM5 a cancer diagnosis qualifies as a traumatic event (APA, 2013), and there have been reports of PTSD symptoms not only in the cancer patients

themselves but also in close family members who go through the traumatic experience with them (Bruce, 2006; Kangas et al., 2002).

Various studies indicate a high correlation between symptoms of depression and anxiety and elevated mortality for almost all cancers (Jefford et al., 2008; Kye et al., 2012; Pandey et al., 2006; Song, 2011; Su et al., 2004; Yu et al., 2006). These psychological effects are also relevant because they are intimately related to the cancer's development, progression, or resurgence (Lutgendorf et. al, 2005; Moreno-Smith, et. al, 2010), which means that addressing these issues as early as possible only better the patients prospects of overcoming the disease.

The Institute of Medicine of the National Academies (IOM) and the American National Research Council (NRC) have found that a cancer patient is also prone to experience some inability to make plans due to a fear of the future, particularly a fear of recurrence and they can also suffer changes in their sexual function and/or reproductive ability which can then pertain to other distressful preoccupations. This fear of cancer recurrence has been proven to be one of the most common problems to be reported by cancer patients and is considered a multidimensional construct that can vary from a normal and expected reaction to a clinically significant one (Baker et. al, 2005; Thews et. al, 2012). In a systematic review of 68 quantitative studies that evaluated the fear of cancer recurrence, it was found that, on average, 73 percent of cancer survivors reported a fear of recurrence to some degree, 49 percent reported a moderate to high degree of fear of recurrence, and 7 percent reported a high degree of fear (Simard et. al, 2013).

3. Psychological Impact of Distress in Cancer Patients

In recent years researchers have begun to develop a profound understanding of the complex relationship between psychological distress and cancer progression. There are links between psychological factors and the onset of cancer, but these links seem to be more significant when the psychological factors are associated with cancer progression (Lutgendorf et. al, 2010; Ross, 2008). Negative psychological aspects such as depression and hopelessness may have a direct impact on disease progression and survival probability (Steel et al, 2007; Watson et. al, 1999) augmenting the former and reducing the latter. Chronic stressors and anxiety can be considered an important risk factor not only for cancer occurrence but also for growth and metastasis (Chida et al, 2008; Garsen, 2004; Sood et. al, 2006; Thaker et. al, 2006).

Although the way these psychological factors affect patients always differs depending on the idiosyncrasies of the patient's condition including prognosis,

treatment type and pain, which are mainly determined by the cancer's characteristics namely type and stage (Ciaramella & Poli, 2001), there is a bio-neurological explanation for the impact of distress on cancer progression (Yuan, Wang, Li, & Huang, 2010) (see Fig.1).

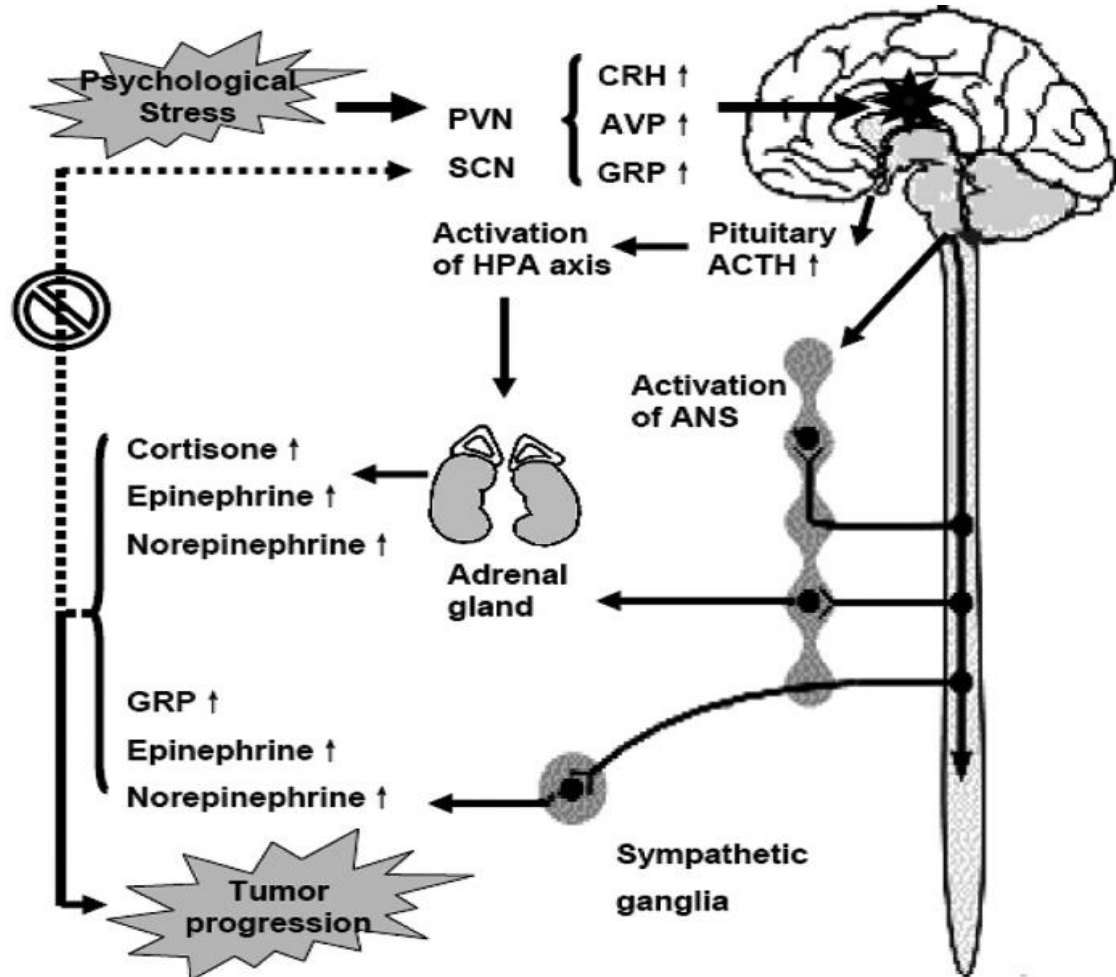


Fig. 1 The bio-neurological model for the impact of distress on cancer progression (Yuan, Wang, Li, & Huang, 2010)

According to this model, alterations to stress-related neuroendocrine transmitters when under psychological distress can lead to a modulation of the chief mechanism against tumor cells, immune cells responses. The impact of distress on the immune response is mediated by a complex signal network between the immune, endocrine, and nervous systems, and the chronic stressors are associated with a suppression of immune functions (Reiche, Nunes, & Morimoto, 2004). For instance, stress hormones affect the immune function through receptors present on immune cells, and the immune cells in turn modulate the activity of the hypothalamus by producing cytokines (small proteins that are important in cell signaling and function regulation). Glucocorticoid receptors (GRs) expressed on a variety of immune cells,

which bind cortisol, interfere with the function of nuclear factor- κ B (NF- κ B), which regulates the activity of cytokine-producing immune cells. Adrenergic receptors (ARs) bind epinephrine (EPI) and norepinephrine (NEPI) to activate the cyclic adenosine monophosphate (cAMP) response element-binding protein (CREB); CREB induces the transcription of genes encoding for a variety of cytokines. Changes in gene expression result in a shift of immune response from T-helper lymphocyte type 1 cells (Th1) to T-helper lymphocyte type 2 cells (Th2), which impairs the immune responses against tumor cells (Glaser & Glaser, 2005).

In sum, psychological support for cancer patients is of paramount importance because when their psychological needs go unanswered it affects their general well being and, may impact the progress of the disease. The patients psychological condition also interferes with the physical treatment of the disease since, if left unattended, psychopathology as well as stress tend to influence the patients will to adhere to the treatment (Charmaz, 2000).

4. Psychological Counseling in Cancer Patients

A psychological intervention must be a part of any good-quality health care by managing the psychological, social and behavioral aspects of the patients life, thusly promoting better health and quality of life (Kroenke et al., 2006). This is especially true for cancer patients because the impacts the disease has on their lives surpasses, as we have established, the physical aspect. Quality of life (QoL) can be defined as the state of complete physical, psychological, and social well-being (WHO, 1947) but it is also the perception of life, objectives, values, standards, and interests in the framework of culture (Dehkordi, Heydarnejad, & Fatehi, 2009). This means that QoL may be seen as a useful outcome measure regarding the effectiveness of psychological interventions.

An oncological patient's counseling may vary from patient-education sessions (in group or individually), to solo counseling sessions, group counseling sessions, or family counseling sessions. All of which are always supported by information from other professionals in an interdisciplinary approach to health care. Whichever the approach to each patients situation, psychological interventions adjacent to oncological treatment aim for the patients to achieve psychological stability by removing or at least reducing the issues witch ail them (Gergurek et al., 2010). Patient-education sessions tend to focus on offering the patients (and sometimes their families) a better understanding of their illness as well as an empowerment of the patients own resources to deal with the psychosocial effects it may have (Andersen, 1992). Solo counseling sessions are

between the patient and a single therapist and can have multiple approaches to the patients problems, which vary depending on the therapists model of intervention (psychodynamic, cognitive-behavioral, systemic, humanist) and the specific intervention technique (in idem). Group counseling is an intervention where a group of patients with similar issues meet simultaneously with one or more therapists to discuss their issues with each other and with the therapist (in idem). Family counseling may include all family members or just two and usually focuses on the relationships of the patients and how the illness of one can be affecting the familial system (in idem).

There have been conducted well over three-hundred studies of psychological interventions with cancer patients over the past sixty years (Newell, Sanson-Fisher, & Savolaine, 2002). Analysis of these various trials lead to the general consensus that different forms of psychological intervention, that teach relaxation and stress management techniques, facilitate the ventilation of the patient's feelings and anxiety improving their general quality of life (Antoni et al, 2006; Coyne, Stefanek, & Palmer, 2007; Spiegel, 2002). These types of psychological intervention, however, are not the only ones to be associated with significant small-to-medium effects on the relief of emotional distress and increase of QoL (Faller et al., 2013). A meta-analysis of 198 studies with 218 treatment-control comparisons concluded that significant small-to-medium effects on the relief of emotional distress and increase of QoL were present in all individual and group psychotherapy and psycho-education interventions, with relaxation training presenting a higher short-term effect (in idem). Furthermore, a different meta-analysis of 20 studies conducted not only with the cancer patients but also their partners, showed that the inclusion of the partner in the intervention may have a small although beneficial effect in regards to the QoL of the patients and their partners (Badr & Krebs, 2013).

Regarding the effectiveness of psychological interventions' influence on cancer progression and survival the results aren't very consensual since there exist various studies with different results and conclusions (Coyne, Stefanek, & Palmer, 2007; Kaufman, 2009; Newell, Sanson-Fisher, & Savolaine, 2002; Spiegel, 2002; Stefanek, Palmer, & Thombs, 2009). One study with patients with breast cancer on stage 2 to 3 of the disease in the weeks post mastectomy randomly assigned patients either to standard care or 4 months of weekly and 8 months of monthly sessions of cognitive behavioral intervention (e.g. relaxation). Results showed that patients that underwent intervention presented a significant reduction in overall mortality rates and a reduced risk of breast cancer recurrence at a median of 11 years follow-up (Andersen et al, 2008). Other recently completed investigations demonstrate that with cognitive behavioral interventions, combining relaxation-based techniques with cognitive

behavioral strategies it is possible to alter negative thinking and to build interpersonal coping skills. Furthermore psychological distress decreases while using relaxation as a coping strategy to manage stress and deal with distressful situations (Andersen, Shelby, & Golden-Kreutz, 2007; Phillips et al, 2008; Witek-Janusek et al, 2008).

The patients point of view can be an essential part to a more effective counseling or therapeutic intervention. Thusly the ascertainment of the priority areas deemed distressful by the patient may be a useful information when it comes to planning the therapeutic intervention.

5. Objectives and study rational

This study intends to shed some light on the main areas that patients indicate as priorities for counseling. Using an idiographic measure we aim to better assess patients' issues and types of issues as a means to facilitate the therapists capacity to help and improve oncological counseling (Sollner et al., 2001). In 1988 Slevin and colleagues acknowledged that outcome measures focused on patient's concerns were of extreme importance to facilitate a more appropriate form of health care, and in all the years past that as only become more of a reality (Slevin et al., 1988). Thusly the more involved in their care process the patients are, the likelier the process is to succeed (Firzpatrick et al., 1998). However even if oncological patients are, as we've seen, subject to highly distressful situations they may not exhibit high levels of emotional distress and with strong social support and a high coping capacity they may not feel need for psychological counseling (Sollner et al., 2001). This is a vital information when because the patients level of emotional distress as well as their perception of that distress will determine their willingness to accept or adhere to the proposed counseling, just as their do too (Clover, Mitchell, Britton, & Carter 2014). Four of the main idiographic instruments are the Psychological Outcome Profiles (Asworth et al., 2014), the Goal Attainment Scaling (Kiresuk & Sherman, 1968), the Target Complaints (Battle et al., 1966), and the Simplified Personal Questionnaire (Elliott, Mack & Shapiro, 1999), all these instruments share with the common goal of assessing the impact of the interventions from the point-of-view of the patient for the betterment of the therapeutic process (Sales & Alves, 2014). The idiographic measure was chosen over a more common interviewing process for the main reason that simple interviews would be to open to achieve our goal whereas an interview to construct an idiographic or personalized outcome measure provides a previous framework and facilitates both the analysis and its comparison to other studies.

With this in mind, the study is meant to appraise what are the most important problems cancer patients feel the disease causes and how they prioritize them, so that a base line of psychological counseling for cancer patients could be achieved. To do so, the idiographic measure chosen was the Personal Questionnaire, because it is a well crafted instrument which as shown its dependability on various previous studies (Sales, Alves, Evans & Elliott, 2014). In addition to the appraisal of problems and priorities the level of emotional distress of the patients will also be scrutinized in order to assess their need for psychological counseling. The levels of emotional distress will also be related to the clinical (e.g. type and stage of cancer) and socio-demographic (e.g. age and gender) characteristics of the patients, in order to identify eventual profiles of patients with different needs in psychological counseling.

Summarizing, our study intends to fulfill three main goals: to assess the general emotional distress of the cancer patients; to identify patients problems and priorities for counseling; and to explore the relationship between the patient's emotional distress and the personal and disease variables.

|

II - Method

1. Participants

The sample was comprised of 51 cancer patients, ages 21 to 80, being the gender distribution fairly equal with the women only slightly more represented (58%). Over 80% of the patients were married and most (36.7%) had two children. The majority of patients (48%) only had the basic literary abilities with only two of them (4%) having a Master's Degree or a Doctorate. In general the patients' sense of socioeconomic difficulties was low with only 10% considering maximum sense of difficulties and nearly 40% viewing them as minimal. Regarding clinical characteristics, most patients (37.3%) were in the treatment phase and had a digestive (45.1%) related cancer (see Table 1).

Table 1: **Patients' socio-demographic and clinical characteristics (n= 51).**

Characteristics	Mean (SD)
Age	58,35 (13,44)
	Frequency (%)
Gender	
Male	21 (42)
Female	29 (58)
Literary abilities	
4th grade	24 (48)
6th grade	8 (16)
9th grade	4 (8)
12th grade	9 (18)
Bachelor's Degree	3 (6)
Master's Degree / Doctorate	2 (4)
Marital State	
Single	5 (10,2)
Married	40 (81,6)
Widowed	2 (4,2)
Living Together	1 (2)
Divorced	1 (2)

Number of Offspring	
0	6 (12,2)
1	12 (24,5)
2	18 (36,7)
3	9 (18,4)
4	2 (4,2)
8	1 (2)
9	1 (2)
Sense of Socioeconomic Difficulties	
Minimal	19 (38,8)
2	7 (14,3)
3	5 (30,6)
4	3 (6,1)
Maximal	5 (10,2)
Phase of the Disease	
Diagnosis	3 (6.1)
Treatment	19 (38.8)
Advanced Disease	13 (26.5)
Recurrence	3 (6.1)
Survival	11 (22.5)
Diagnosis Group	
Digestive	23 (45.1)
Skin, Soft Tissue and Bone	11 (21.6)
Urology and Gynecology	5 (9.8)
Lung	5 (9.8)
Other	7 (13.7)

2. Instruments

2.1. Socio-demographic and Clinical Questionnaire

The socio-demographic questionnaire was created by the researchers to assess socio-demographic variables (age, gender, education, marital status, no children, socioeconomic status) and clinical variables (diagnosis, stage of disease, etc.) (Annex 4).

2.2. 10-item Clinical Outcomes in Routine Evaluation questionnaire (CORE-10)

The CORE-10 (Evans et al., 2000; Sales, Moleiro, Evans & Alves, 2012) is a generic measure used to review alterations of the psychological distress. It is shortened version of the CORE-OM, integrating only 10 of 34 total items, consisting therefore in a brief measure of screening and clinical review. The final results are calculated by adding the individual item scores and dividing by the total number of questions answered to attain a mean score ranging from 0 to 4. (Annex 1)

2.3. Distress Thermometer (DT)

The Distress Thermometer (Decat, Laros & Araujo 2009; Patrick-Miller, Broccoli, Much & Levine, 2004) is a questionnaire presented as a scale which calls for patients to assign a level to their emotional distress in the past week, from 0 (no distress) to 10 (extreme distress) with a cut-off at 4. This questionnaire is mainly used as a screening instrument (Annex 3).

2.4. Simplified Personal Questionnaire (PQ)

The *Simplified Personal Questionnaire* (Elliott, Mack, & Shapiro, 1999; Sales et al., 2007) is an individualized change measure consisting of approximately 10 problems that a patient would like to work on in therapy. The PQ is thus constructed in a semi-structured interview with the duration of 45 minutes. The interview is meant to facilitate the patients description of their issues, which are then written on individual notes to be subsequently organized onto a standard form. The patients are then given the instruction to score each issue, on a scale of 1 (not at all) to 7 (maximum possible), according to the discomfort it has caused them in the past week. Each issue has an individual score but the mean score of all issues is also taken into account regarding the patients' emotional distress, for which the cut-off is a mean score of 3.25 (Elliott et al., 2016) (Annex 2).

2.5. Therapist's Adherence to PQ Protocol Questionnaire

The Therapist's Adherence to Protocol Questionnaire is an instrument created by the researchers to assess the level of adherence to the PQ protocol by the therapist in each PQ application, for each of the steps as well as for the general adherence, ranging from 0(null adhesion) to 5(full adhesion) (Annex 5).

The Simplified Personal Questionnaire Protocol is composed of six stages, starting with item generation where the items generated for the PQ should be the most important in the client's view. However, an attempt should be made to include at least one problem regarding symptoms, mood, specific activities (e.g. work), relationships, and self-esteem. This means that if the client does not list a problem in a particular area, the interviewer should ask the client if there are any difficulties in that area that s/he wants to work on in therapy. The second stage is item clarification in which the interviewer helps the client to clarify his/her items and, if necessary, to rephrase the goals into problems. The interviewer begins by writing each problem onto a separate index card, revising it in the process. Refining PQ items requires discussion with the client to make sure that the PQ reflects his/her chief concerns. PQ items should be present as problems or difficulties, and should be worded "I feel," "I am," "I can't," "My thinking,". After writing down the items, the interviewer asks the client if anything has been left out, adding further items as needed, until the client feels that the list is complete. The interviewer then reviews the items with the client, asking the client to revise or confirm them. If the client has generated more than 10 items, the interviewer asks the client to delete or combine repetitive items. If there are still more than 10 items, the interviewer asks the client if s/he wants to drop any. The interview should not force the client to generate exactly 10 items; but try to obtain 8-12 items where possible. The next stage is item priority where the interviewer asks the client to sort the index cards into order, with the most important concern first, writing the rank order of the item on the card. In the item scoring stage the interviewer gives the client a blank PQ form and the rank-ordered index cards, and asks the client to use the blank form to rate how much each problem has bothered him/her during the past week. The item duration stage is the fifth stage where using the Personal Questionnaire Duration Form the interviewer can find out how long each problem has bothered the client at roughly the same level or higher as it does now. The sixth and final stage is the item fill-in in which the interviewer types or writes the PQ items onto a blank PQ form, making at least 10 copies for future use. In doing so, it is a good idea to leave 2 spaces blank for the client to add more items later, in case his/her problems shift over.

3. Procedure

3.1. Data collection

The data was collected at Porto's Portuguese Institute of Oncology (IPO) by two psychologists on the first consultation with patients referred to the psychooncology department. The patients were selected by the psychologists from their daily consultation (consecutive sampling) following an exclusion criteria of underage patients, patients whose consultation was given in the inpatient ward and also patients whose first consultation was given by an intern. Patients who demonstrated severe emotional deregulation, severe cognitive limitations and severe physical limitations or discomfort were also excluded. This meant that from an original 83 patient consultations 39,8% were excluded from the study, resulting in a total of 51 patient considered (see Fig. 2). The data collection followed each instruments protocol and at the end of each session, the therapists would respond to the Adherence to PQ Protocol Questionnaire so that the adherence to the PQ protocol could also be considered data in and of itself. This study was subjected to and approved by the ethics committee of Porto's IPO. The data for the study was obtained over the span of four months, between December 2014 and March 2015. All patients who arrived at the consultations were asked, at the beginning of the session, if they would sign a disclosure agreement and only then were subject to the study's protocol evaluation.

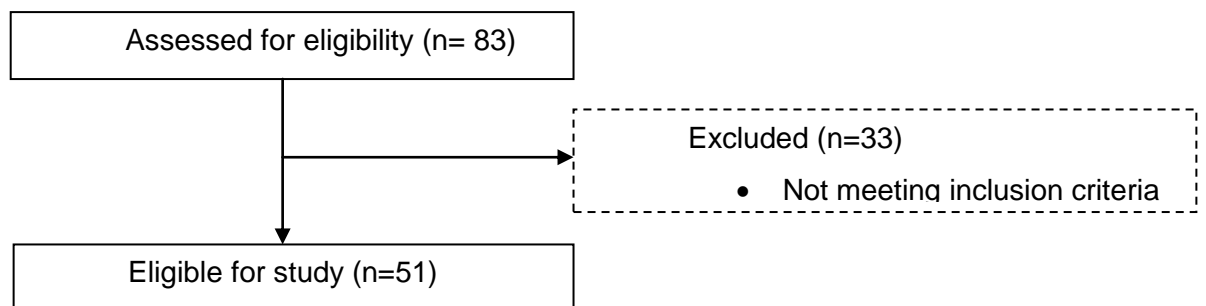


Fig.2 Patient Flow Chart

3.2. Data analysis

To analyze the data for this study we began by assessing the quality through two procedures. First the PQ items' quality was assessed then the therapists adherence to the PQ protocol was also scrutinized. The second step of the data analysis consisted on the examination of patients emotional distress, as well as its relationship to personal and clinical variables (e.g. age, diagnosis). Finally the PQ data was thematically analyzed.

3.2.1. Quality of PQ items

For the analysis of the quality of the PQ items we used the item Rating System proposed by Elliott (2012), which classifies the quality of each free-text item according to the following criteria: 1. Well-formed item: Specific, personal difficulty that is reasonably a focus for psychotherapy; 2. Items concerning Vague personal difficulties (e.g., relationships); 3. Items formulated as Goals instead of problems (e.g., get along better with people); 4. Items concerning General societal problems (e.g., general economic situation); 5. Other item quality issues (e.g. if the free text was in the patient's own words or if it was described by the therapist), meaning that only the first classification indicates high quality the rest describe various quality issues. Two independent judges classified each free text answer into the category that fits the item best with the discrepancies being discussed in order to reach a consensus.

3.2.2. Therapist adherence to PQ protocol

A descriptive analysis of the Therapist's Adherence to Protocol Questionnaire was carried out.

3.2.3. Emotional distress of oncological patients

For the analysis of the emotional distress of the patients we used a quantitative analysis of the CORE-10, the Distress Thermometer, and the PQ (mean scoring, duration).

The relation between emotional distress and, clinical and socio-demographic variables was determined as well through t-student and ANOVA statistical analysis tests.

3.2.4. Thematic analysis of the PQ items & Describing patients problems and priorities

This analysis was based on the replication of the strategy used by Ashworth (Sales et al., 2016) on the qualitative analysis of PSYCHLOPS (Ashworth et al., 2004) - another well-studied individualized outcome measure - items. To begin with the free text responses were listed. Further analysis grouped responses into subthemes. Subthemes were derived by allocating responses into the simplest inclusive thematic categories if a response did not clearly fit into an existing subtheme then a new subtheme was created. Two independent judges classified each free text answer into the category that fits the item best with the discrepancies being discussed in order to reach a consensus. The subthemes were then organized in six broader categories following Elliott's PQ Content Categories (Robert, Lloyd & Susan, 2015) and an extra one for those which didn't fit any of the six: Interpersonal difficulties; Unresolved traumatic events; Self-related issues; Life functioning/skills/adjustment issues; Depression; Stress/anxiety; and Other problems. The analysis of this data was made in the light of both the number of items generated and the number of patients, regarding each category.

III - Results

1. Quality of PQ items and Adherence to PQ protocol

The quality of the PQ items was globally high, with 74% (n=144) well formed items. There were however some quality issues, chief among them was the existence of items describing vague personal difficulties (22%, n=43) (see Table 2).

Table 2: **Item quality classification (n=195)**

Item quality categories	n (%)
Well-formed	144 (73.85)
Vague personal difficulties	43 (22.05)
Goal	1 (0.51)
General societal problems	4 (2.05)
Other	3 (1.54)

Even though the items were globally well formed, the therapists had difficulties following the PQ protocol to the letter with the average general adherence situated in the middle of the adherence scale (see table 3). The most difficult protocol components to follow were Item Priority (2.04 out of 5) and Item Clarification (2.64 out of 5) being Item Scoring (4.18 out of 5) and Item Fill-In (4.11 out of 5) the ones where the protocol was more strictly followed.

Table 3: **Therapists Self-Rated adherence to PQ protocol (0 to 5)**

Protocol components	Mean (SD)
Item Generation	3.33 (1.00)
Item Clarification	2.64 (1.11)
Item Priority	2.04 (1.52)
Item Scoring	4.18 (1.19)
Item Duration	3.93 (1.42)
Item Fill-In	4.11 (0.65)
General	3.45 (0.93)

2. Emotional state of oncological patients

The patients emotional state was not considered disturbing in two of the emotional state scales. The distress thermometer presented a slight elevation (5.94) from medium distress (cut-off is 4) and the CORE-10 results were (1.41) atop the cut-off point (10 for the CORE-OM which means 1 for the CORE-10). In contrast, the PQ average score results were situated on the dysfunctional range (5.13, above the cut-off point of 3.25) revealing a big discomfort felt by the patients regarding the problems described, as can be seen in Table 4.

Table 4: **Patients' emotional state scoring**

Emotional State Scales	Mean (SD)
CORE-10	1.41 (0.72)
Distress Thermometer	5.94 (2.59)
PQ Average Score	5.13 (1.16)

Regarding the PQ specifically, the high discomfort gains even more relevance when we relate each patients average score to the cut-off (3.25) and conclude that only 3 patients were bellow it, one was on it and only three more were slightly above it (below 4).

3. Problems and priorities of oncological patients

The patients' problems and priorities were consistently distributed between the six broad categories achieved. The majority of the problems were related to life functioning issues (20.41%, N=40) and anxiety (19.39%, N=38). The rest were evenly divided between depression (16.33%, N=32), interpersonal difficulties (14.29%, N=28), other (14.80%, N=29), and self related issues (11.22%, N=22), while only 3.57% (N=7) were due to unresolved traumatic events. These percentages concern the PQ items formed.

Regarding the number of patients that present each type of issue, most (80%) presented life functioning issues, the majority of which were linked to adapting to the restrictions caused by the disease, like "I feel limited by my health, I can't go out as I would like". These were followed by patients with depression issues (66.66%) like "I've lost the taste to do most things", and only 15.55% had unresolved traumatic events issues for example "Reliving negative experiences". Anxiety issues were presented by 57.77% of the patients, most of them related to some kind of fear such

as "Fear that the treatment is not being effective", while 48.88% of the patients had interpersonal difficulties issues, mainly with family, such as "The relationship with the wife has changed a lot" and another 48.88% had self related issues mostly related to self image like "Felling bad about how I look". Seeing as the broad category "other" presented one of the highest percentages, it is important to highlight that 53.33% of the patients had these types of issues. Half of these patients presented family concerns such as "Concern for the health of the children" while a quarter of them presented recurring negative thoughts (Table 5).

Table 5: Patients' problems and priorities by item (N=195) & by patient (n=45)

Subthemes (n)	Broad Categories	N (%)	n
Combine family and work (1)			
Being a Smoker (1)			
Frustration (1)			
Financial difficulties (3)			
Pain (2)			
Making decisions for the future (1)			
Sexual difficulties (3)			
Adapting to the restrictions caused by the disease (21)			
- unable to help grandson	Life	40	36
- dietary changes	Functioning	(20.41)	
- not having strength	Issues		
- being taken care of / dependent on others			
- lack of free time			
- management of household chores			
- not working			
- general			
Disease Effects (3)			
- losing your voice			
- using ostomy bag			
Ability to manage Stress (1)			
Panic Attacks (1)			
Anxiety regarding treatment (4)			
Fear (20)			
- surgical intervention			

- treatment efficacy	Anxiety	38	26
- relapse		(19.39)	
- to die			
- disease progression			
- suffering			
- side effects of treatment			
- general			
<hr/>			
Anhedonia (2)			
Sleeping problems (9)			
Sadness for reaching the end of life (1)			
Weariness (3)			
World View (2)			
Suicidal Ideation (1)	Depression	32	30
Sadness - general (2)		(16.33)	
Despair (2)			
Loneliness (4)			
Lack of energy (2)			
De-motivation (1)			
Forebodings (1)			
<hr/>			
Recurring Negative Thoughts (6)			
Uncertainty towards the future (3)			
Uncertainty regarding life expectancy (1)			
Difficulties in identifying the problems (1)			
Body tension (1)	Other	29	24
Family concerns (12)		(14.80)	
- General concern			
- general concern for the children			
- concern for the spouse			
- concern with leaving others			
- concern for the health of the children			
<hr/>			
Difficulty Asking for Help (1)			
Family Relationships (10)			
- be a burden to the children			
- change in the relationship with the spouse			
- impatience			
- convivial difficulties			
- communication difficulties	Interpersonal Difficulties	28	22
- discuss the disease		(14.29)	
- difficulty in relationships			
- lack of support from the children			

- general			
Interpersonal relationship (11)			
- Irritability / Aggressiveness			
- avoidance / isolation			
- negative view of others			
- general			

Feeling Unfulfilled (1)			
Sense of Futility (3)			
Self image / Self esteem (8)	Self Related	22	22
Feeling of injustice (7)	Issues	(11.22)	
Vulnerability (1)			
Powerlessness (1)			
Lack of Concentration (1)			

Longing for the deceased partner (1)			
Inability to Overcome the Disease (1)	Unresolved	07	07
Reliving negative experiences (1)	Traumatic	(3.57)	
Confrontation with people in similar situations (1)	Events		
Disease Acceptance (2)			
Acceptance of treatment (1)			

4. Patients' emotional distress related to personal and disease variables

The correlation between the patients age and the distress scales indicated that it was only significant regarding the CORE-10 ($r=-0.366$, $p= 0.009$). The results indicated that there was a moderate negative correlation between the patients' age and the CORE-10, which means that younger people feel more distressed (Table 6).

Women presented a slightly higher degree of emotional distress on all scales (Distress Thermometer $M=6.9$, $SE=0.52$; C $M=1.54$, $SE=0.16$, PQ $M=5.32$, $SE=0.23$) than men (DT $M=5.07$, $SE=0.48$; C $M=1.27$, $SE=0.13$, PQ $M=4.93$, $SE=0.27$). However, this difference was only statistically significant for the Distress Thermometer, $t(46)=-2.58$, $p=0.013$. (Table 7).

Table 6: Age related to psychological distress

Subject's age related to:	Pearson Correlation	Sig. (2-tailed)	N
Distress Thermometer	-0.236	0.102	49
Core10Total	-0.366	0.009	50
PQ Mean Score	-0.134	0.384	44

Table 7: Gender related to psychological distress

	Gender						Sig. (2-tailed)	95% CI for Mean Difference	t	df
	Male			Female						
	M	SD	n	M	SD	n				
Distress Thermometer	5.0741	2.47955	27	6.9048	2.38547	21	0.013	-1.83069	-2.580	46
Core 10 Total	1.2682	0.68024	29	1.5422	0.71187	20	0.180	-0.27402	-1.360	47
PQ mean score	4.9330	1.28284	23	5.3189	1.01965	20	0.286	-0.38594	-1.080	41

Moreover, having undergone, or not, a previous treatment, (either chemotherapy, radiotherapy or surgery) did not significantly associate to the levels of emotional distress shown by the patients on the CORE-10 and the Distress Thermometer. In contrast, patients who have undergone chemotherapy in the past indicated problems with a significantly lower intensity level in PQ than patients who have never undergone chemotherapy (Table 8).

Table 8: **Previous treatments related to psychological distress**

	Previous Treatment of Chemotherapy						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	n	M	SD	n			
Distress Thermometer	6.4800	2.72519	25	5.5652	2.23253	23	0.212	0.91478	1.266
Core 10 Total	1.3169	0.66284	25	1.5352	0.76085	24	0.289	-0.21830	-1.072
PQ mean score	5.5760	1.10126	22	4.6779	1.06029	22	0.009	0.89812	2.756
	Previous Treatment of Radiotherapy						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	n	M	SD	n			
Distress Thermometer	6.0000	2.49878	42	6.3333	2.87518	6	0.765	-0.33333	-0.300
Core 10 Total	1.4132	0.71950	43	1.5000	0.72938	6	0.783	-0.08682	-0.276
PQ mean score	5.0665	1.12629	37	5.4464	1.38040	7	0.434	-0.37988	-0.790
	Previous Surgery						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	n	M	SD	n			
Distress Thermometer	5.8235	2.21459	17	6.1613	2.69687	31	0.661	-0.33776	-0.441
Core 10 Total	1.4542	0.64842	17	1.4076	0.75544	32	0.830	0.04661	0.215
PQ mean score	4.8569	1.21613	16	5.2813	1.12104	28	0.248	-0.42435	-1.171
	No Previous Treatment						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	n	M	SD	n			
Distress Thermometer	5.9767	2.46391	43	6.6000	3.20936	5	0.606	-0.62326	-0.520
Core 10 Total	1.4578	0.71065	44	1.1244	0.74624	5	0.327	0.33338	0.990
PQ mean score	5.0577	1.13484	40	5.8194	1.36790	4	0.215	-0.76171	-1.260

Referring to the influence of current treatments on the patient's emotional distress, it did not differ significantly between the three types of treatment or the non existence of treatment (Table 9). This means that for the patients the type of treatment, or the existence of any, and the moment for it have no relevant association to their emotional distress.

Table 9: **Current treatments related to psychological distress**

	Current Treatment of Chemotherapy						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	n	M	SD	n			
Distress Thermometer	6.0000	2.25320	27	6.0952	2.87932	21	0.898	-0.09524	-0.129
Core 10 Total	1.4691	0.74708	27	1.3682	0.68340	22	0.627	0.10095	0.489
PQ mean score	5.2949	1.08388	25	4.9060	1.24994	19	0.276	0.38887	1.103
	Current Treatment of Radiotherapy						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	n	M	SD	n			
Distress Thermometer	6.0476	2.35768	42	6.0000	3.74166	6	0.966	0.04762	0.043
Core 10 Total	1.4527	0.70171	43	1.2167	0.83287	6	0.454	0.23605	0.756
PQ mean score	5.1046	1.14183	38	5.2685	1.38351	6	0.752	-0.16388	-0.318
	Current Surgery						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	N	M	SD	N			
Distress Thermometer	5.9778	2.52703	45	7.0000	2.64575	3	0.502	-1.02222	-0.677
Core 10 Total	1.4036	0.71569	46	1.7333	0.73711	3	0.444	-0.32971	-0.772
PQ mean score	5.0916	1.18625	41	5.6111	0.67358	3	0.461	-0.51955	-0.744
	No Current Treatment						Sig. (2-tailed)	95% CI for Mean Difference	t
	No			Yes					
	M	SD	N	M	SD	n			
Distress Thermometer	6.5000	2.72845	28	5.4000	2.08756	20	0.137	1.10000	1.513
Core 10 Total	1.4034	0.71388	29	1.4533	0.73066	20	0.813	-0.04989	-0.238
PQ mean score	5.1621	1.18876	26	5.0763	1.15153	18	0.813	0.08585	0.239

Regarding the influence phase of treatment may have had on patient's emotional distress the results show that the average distress did not differ significantly between the five phases for each scale (Table 10). Which means that the different phases of treatment in which the patients may find themselves had very little relation to the change of their emotional distress.

Table 10: **Phase of treatment related to psychological distress**

		M(SD)	Std. Error	95% CI for mean	
				LB	UB
Distress Thermometer	Diagnosis	5.0000 (3.00000)	1.73205	-2.4524	12.4524
	Treatment	6.0556 (2.95997)	0.69767	4.5836	7.5275
	Advanced Disease	6.5833 (2.64432)	0.76335	4.9032	8.2635
	Recurrence	4.6667 (1.52753)	0.88192	0.8721	8.4612
	Survival	5.5455 (1.86353)	0.56187	4.2935	6.7974
Core10Total	Diagnosis	0.9074 (0.68892)	0.39775	-0.8040	2.6188
	Treatment	1.3813 (0.73358)	0.16829	1.0277	1.7349
	Advanced Disease	1.2796 (0.73727)	0.21283	0.8112	1.7481
	Recurrence	1.2667 (0.32146)	0.18559	0.4681	2.0652
	Survival	1.6818 (0.74272)	0.22394	1.1829	2.1808
PQ mean score	Diagnosis	4.3750 (1.94454)	1.37500	-13.0960	21.8460
	Treatment	4.9403 (0.96232)	0.23340	4.4455	5.4350
	Advanced Disease	5.3601 (1.43647)	0.43311	4.3951	6.3251
	Recurrence	5.9167 (0.58926)	0.41667	0.6224	11.2109
	Survival	5.0458 (1.10299)	0.34880	4.2568	5.8349
		Sum of			
		Squares	df	Mean Square	F
Distress Thermometer	Between Groups	14.405	4	3.601	0.534
	Within Groups	283.255	42	6.744	
	Total	297.660	46		
Core10Total	Between Groups	1.828	4	0.457	0.880
	Within Groups	22.338	43	0.519	
	Total	24.166	47		
PQ mean score	Between Groups	3.591	4	0.898	0.657
	Within Groups	50.529	37	1.366	
	Total	54.121	41		

As for diagnosis, the association to the patient's emotional distress did not differ significantly between the five cancer groups for each scale although on the PQ mean scores there was a slightly stronger relation (Table 11).

Table 11: **Diagnosis related to psychological distress**

		M(SD)	Std. Error	95% CI for mean	
				LB	UB
Distress	Digestive	6.2273 (2.58073)	0.55021	5.0830	7.3715
Thermometer	Skin, Soft Tissue, Bone	5.8182 (2.08893)	0.62984	4.4148	7.2215
	Urology and Gynecology	5.8000 (3.76829)	1.68523	1.1211	10.4789
	Lung	5.2500 (4.11299)	2.05649	-1.2947	11.7947
	Others	5.7143 (2.13809)	0.80812	3.7369	7.6917
Core10Total	Digestive	1.4136 (0.67089)	0.14304	1.1162	1.7111
	Skin, Soft Tissue, Bone	1.4000 (0.62290)	0.18781	0.9815	1.8185
	Urology and Gynecology	1.2000 (1.08858)	0.48683	-0.1516	2.5516
	Lung	0.9444 (0.70702)	0.31619	0.0666	1.8223
	Others	1.8714 (0.62106)	0.23474	1.2970	2.4458
PQ mean score	Digestive	4.9417 (1.02680)	0.22960	4.4612	5.4223
	Skin, Soft Tissue, Bone	5.4383 (1.14242)	0.38081	4.5601	6.3164
	Urology and Gynecology	6.,3688 (0.67866)	0.33933	5.2889	7.4486
	Lung	4.4375 (1.83002)	0.91501	1.5255	7.3495
	Others	4.9405 (1.01461)	0.38349	4.0021	5.8788
		Sum of Squares	df	Mean Square	F
Distress	Between Groups	4.338	4	1.084	0.150
Thermometer	Within Groups	318.479	44	7.238	
	Total	322.816	48		
Core10Total	Between Groups	2.975	4	0.699	1.405
	Within Groups	22.386	45	0.497	
	Total	25.181	49		
PQ mean score	Between Groups	9.872	4	2.468	2.002
	Within Groups	48.078	39	1.233	
	Total	57.950	43		

|

IV - Discussion

The main purpose of this study was to ascertain what our sample of cancer patients views as the most important issues ailing them. We found that the third most important type of issue for the patients was depression, mainly anhedonia. These results were unsurprising as depression tends to always be present in cancer patients in some manner, even when the DSM criteria for major and minor depression are not met many depressive symptoms tend to exist in cancer patients, such as sleeping alterations, anhedonia, and eating alterations (Pasquini & Biondi, 2007).

The second most important issues were the anxiety issues, mostly related to fear of the way the disease will develop. This was expected since a fear of disease progression is a reasonable response to a cancer diagnosis and its treatment options (Herschbach & Dinkel, 2014), and according to a 2013 study 56% of patients diagnosed with cancer for the first time present high fear regarding the progression of the disease (Savard & Ivers, 2013).

Another interesting result was the fact that many patients pointed out the difficulty in dealing with their concern for others, namely their family members, by not wanting to burden them. This is a common result when inquiring cancer patients since the disease can affect the patient autonomy and informal caregivers become a crucial part of their lives (Lim, Kim, Lee, 2013).

Finally we found that the most prominent types of problems for our sample of cancer patients to overcome in therapy were regarding the adaptation to the psychosocial implications of the disease and the limitations it can cause were. A 2011 meta-analysis of interview-based studies supports our findings as it showed that major depression and anxiety are less common in cancer patients than believed while adjustment disorder gains more weight. In 70 different studies with 10071 patients in oncological and haematological settings the prevalence of major and minor depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM) was 14.9% and 19.2% respectively and for anxiety disorders it was 10.3% while adjustment disorder alone presented a prevalence of 19.4% (Mitchell, et al., 2011).

The results obtained by this study were coherent with what we found in the literature (Akechi et al., 2001; Charmaz, 2000; Grassi et al., 2004; Gregurek et al., 2010; Herschbach & Dinkel, 2014; Jacobsen et al., 2000; Kissane et al., 2004; Kornblith, 1998; Lim, Kim, Lee, 2013; Mitchell et al., 2011; Miovic & Block, 2007; Mystakidou et al., 2005; Pasquini & Biondi, 2007; Stanton et al., 2001; Savard & Ivers, 2013) and seem to indicate that in initial psychological counseling with oncological patients therapists should focus on helping them overcome their perceived limitations or to better adjust to their real ones in the quotidian.

Interventions focusing on managing the medical aspects of the illness, the life roles and their changes brought on by the illness as well as managing the psychological consequences of the illness have made significant progress in facilitating the management of both physical and psychological symptoms related to cancer and its treatments (McCorkle et al., 2011). Which goes to show that this approach to psychological counseling with oncological patients seems to be effective by focusing on the types of issues referred by our sample of cancer patients.

Regarding the influence personal and disease variables may have had on the patients emotional distress it should be highlighted that women tend to show higher levels of distress in all of the scales although the values are only significant for the Distress Thermometer. These results are consistent with other studies relating stress and gender, where although both genders report, on average, a similar level of stress women tend to report that their stress levels are on the rise more than men. As well as report higher physical and emotional symptoms of stress (Calvarese, 2015; Campbell & Svenson, 1992; Chaplin, Hong, Bergquist, & Sinha, 2008).

The problems patients with a history of chemotherapy present in the PQ have a lower level of intensity than the problems presented by people who have never undergone the same treatment. These results may be linked to the fact that the people who have already undergone the treatment before have a clearer notion of what to expect from it (Anjos & Zago, 2005). This becomes evident when comparing the issues raised by each group, the categories don't differ significantly but the patients who have undergone chemotherapy present a higher number of life functioning issues like "Being still, not feeling useful", "Being unable to work", or "I feel limited by my health, I can't go out as much as I would like", while patients who have not present more anxiety issues, particularly fears regarding the treatment such as "Fear the treatment isn't going to work", "I feel anxious to start the treatment", and "Fear of the physical pain". That being said, it becomes apparent that it should be given a special attention to the fear patients have regarding the treatment's efficacy and the side effects it may have, for patients undergoing their first chemotherapy treatment.

As to the level of emotional distress the disease has brought upon the patients, it was surprisingly not very elevated in the two principal scales used for its measurement - the Distress Thermometer and the CORE-10. The slight elevation on the distress results may be explained by the sample selection since the patients in a more critical state both physically and emotionally were excluded. A previous study at Porto's IPO showed similarly low results in regards to the Distress Thermometer where 245 patients averaged an emotional distress level of 3.86 (Silva & Castro, 2009).

When it came to the PQ, the level of emotional distress was considerably higher, the difference found between the PQ results and the other two scales may be due to the latter being generic nomothetic anxiety and depression measures and the first an individualized measure which allows the patient to point out sources of psychological distress that are not foreseen in nomothetic measures. A previous study of 2015 supports this as it found that out of 107 patients 74% reported at least one problem in an individualized outcome measure, the Psychological Outcome Profiles (PSYCHLOPS), that was not covered by the nomothetic measure, the CORE-OM (Neves, 2015). For example, the fear patients have regarding the treatment's efficacy and the side effects it may have is not a complaint foreseen in the CORE-10 but was present in the PQ, as well as feelings of injustice or the problems regarding the patients adaptation to the restrictions caused by the disease.

Even though the PQ seems to be a more sensitive measure to the patients problems, following its protocol in an hospital context with an oncological population seems to be challenging. The data referring to therapists adherence to the PQ protocol should be taken into account since out of the protocol's six stages none were followed exactly and two of them were very arduous to uphold - item priority and item clarification. The main reasons for the difficulties in following the protocol exactly were the many tasks a first consultation entails and the limited time frame the therapists had to apply the PQ. Regarding the two specific stages with the least adherence, the main issue was the use of the index cards which the therapists felt was counterproductive and extra time consuming. For these reasons we do not recommend the future use of the Simplified Personal Questionnaire as an investigative instrument in this context, perhaps a shorter individualized self-report measure such as the PSYCHLOPS - the patient has the possibility to develop three items of greater relevance to their clinical status covering three domains, problems, functionality, and perceived well being (Ashworth et al.,2004) - may be more useful and as far as we know a have not yet been used in this context.

This study was not without limitations, the most glaring of which was the size of the sample that limited our capability of extrapolating our results to the general oncological population. The other limitation of our study was already addressed above and regards the adherence to the PQ protocol which was low and therefore may be cause to question the fully accurate depiction of the patients point of view achieved.

V - References

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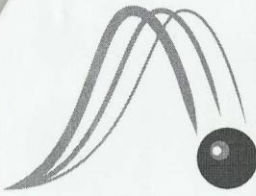
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ANNEX

Annex 1: CORE-10



CORE - 10

Identif. Caso

Data de preenchimento

D D M M A A A A

Identif. Serviço

Identif. Terapeuta

Idade
 Género M F

Fase de preenchimento
 T Triagem
 E Encaminhamento
 A Avaliação pré-tratamento
 P Pré-primeira sessão
 1 Pré-terapia, não especificado
 D Durante Terapia
 U Última sessão
 X Follow up 1
 Y Follow up 2

Episódio

IMPORTANTE - LEIA ANTES DE RESPONDER

Este questionário tem 10 afirmações sobre como se sentiu durante a última semana. Por favor, leia cada afirmação e pense quantas vezes se sentiu assim. Depois, marque a resposta que mais se aproxima da maneira como se sentiu.

Durante a última semana...

	<i>Nunca</i>	<i>Raramente</i>	<i>Às vezes</i>	<i>Muitas vezes</i>	<i>Sempre, ou quase sempre</i>
1 Tenho-me sentido tenso/a, ansioso/a ou nervoso/a	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2 Senti que tenho alguém a quem posso pedir ajuda, se precisar	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3 Tenho sentido que sou capaz de lidar com as coisas que correm mal	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4 Tem-me custado muito falar com as outras pessoas	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5 Senti pânico ou terror	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6 Fiz planos para acabar com a minha vida	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7 Tenho tido dificuldade em adormecer ou em dormir toda a noite	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8 Senti-me desesperado/a ou sem saída	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9 Tenho-me sentido triste	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10 Tenho-me sentido perturbado/a por imagens ou recordações que não quero ter	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

OBRIGADO PELA SUA COLABORAÇÃO

Total a dividir pelo número de itens respondidos. Não calcular se houver dois ou mais itens sem resposta.

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Annex 2: Personal Questionnaire

QUESTIONÁRIO PESSOAL

Data: ___ / ___ / _____

Código Cliente: _____

Instruções: Por favor, indique o grau de mal-estar que cada problema lhe causou na última semana. Muito obrigado.

	Nenhum Mal-Estar	Muito Pouco	Pouco	Mal-Estar Moderado	Grande	Muito Grande	Mal-Estar Total
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

QUESTIONÁRIO PESSOAL

Data: ___ / ___ / _____

Código Cliente: _____

Instruções: Preencher antes de cada sessão. Por favor, indique o grau de mal-estar que cada problema lhe tem causado desde a última consulta. Caso existam novos problemas, por favor acrescente-os e indique o grau de mal-estar. Se algum dos problemas já não fizer sentido, por favor risque-o na lista. Muito obrigado.

	Nenhum Mal-Estar	Muito Pouco	Pouco	Mal-Estar Moderado	Grande	Muito Grande	Mal-Estar Total
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

QUESTIONÁRIO PESSOAL

Data: ___ / ___ / _____

Código Cliente: _____

Instruções: Por favor, pense desde quando é que estes problemas lhe causam mal-estar, com a mesma intensidade que indicou no quadro anterior, ou com maior intensidade.

	Menos de 1 mês	De 1 a 5 meses	De 6 a 11 meses	De 1 a 2 anos	De 3 a 5 anos	De 6 a 10 anos	Há mais de 10 anos
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

QUESTIONÁRIO PESSOAL

Data: ___ / ___ / _____

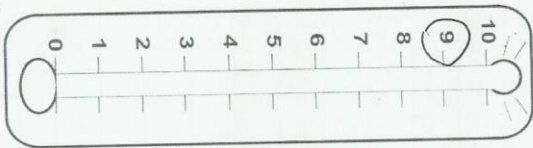
Código Cliente: _____

Instruções: Preencher antes de cada sessão. Por favor, indique o grau de mal-estar que cada problema lhe tem causado desde a última consulta. Caso existam novos problemas, por favor acrescente-os e indique o grau de mal-estar. Se algum dos problemas já não fizer sentido, por favor risque-o na lista. Muito obrigado.

	<u>Nenhum Mal-Estar</u>	Muito Pouco	Pouco	<u>Mal-Estar Moderado</u>	Grande	Muito Grande	<u>Mal-Estar Total</u>
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

AVALIAÇÃO DO SOFRIMENTO EMOCIONAL

INSTRUÇÕES: Por favor, faça um círculo em volta do número (0-10) que melhor descreva o seu grau de *sofrimento emocional* na última semana, incluindo hoje.



Por favor, indique se alguma das situações que se seguem, têm sido um problema para si na última semana, incluindo hoje. Certifique-se se respondeu "Sim" ou "Não" a todas as questões.

	Sim	Não	Problemas Práticos	Sim	Não	Problemas Físico
	<input type="checkbox"/>	<input type="checkbox"/>	Cuidar dos filhos	<input type="checkbox"/>	<input type="checkbox"/>	Aspecto físico
	<input type="checkbox"/>	<input type="checkbox"/>	Tarefas Domésticas	<input type="checkbox"/>	<input type="checkbox"/>	Tomar banho/Vestir-se
	<input type="checkbox"/>	<input type="checkbox"/>	Económicos	<input type="checkbox"/>	<input type="checkbox"/>	Dificuldades respiratórias
	<input type="checkbox"/>	<input type="checkbox"/>	Transporte/deslocação	<input type="checkbox"/>	<input type="checkbox"/>	Alterações urinárias
	<input type="checkbox"/>	<input type="checkbox"/>	Trabalho/Escola	<input type="checkbox"/>	<input type="checkbox"/>	Prisão de ventre
	<input type="checkbox"/>	<input type="checkbox"/>	<u>Problemas Familiares</u>	<input type="checkbox"/>	<input type="checkbox"/>	Diarreias
	<input type="checkbox"/>	<input type="checkbox"/>	Com os filhos	<input type="checkbox"/>	<input type="checkbox"/>	Alimentação
	<input type="checkbox"/>	<input type="checkbox"/>	Com o marido/companheiro	<input type="checkbox"/>	<input type="checkbox"/>	Fadiga Cansaço
	<input type="checkbox"/>	<input type="checkbox"/>	<u>Problemas Emocionais</u>	<input type="checkbox"/>	<input type="checkbox"/>	Febre
	<input type="checkbox"/>	<input type="checkbox"/>	Depressão	<input type="checkbox"/>	<input type="checkbox"/>	Movimentar-se
	<input type="checkbox"/>	<input type="checkbox"/>	Medos	<input type="checkbox"/>	<input type="checkbox"/>	Enfartamento
	<input type="checkbox"/>	<input type="checkbox"/>	Nervosismo/Ansiedade	<input type="checkbox"/>	<input type="checkbox"/>	Memória/Concentração
	<input type="checkbox"/>	<input type="checkbox"/>	Tristeza	<input type="checkbox"/>	<input type="checkbox"/>	Feridas na boca
	<input type="checkbox"/>	<input type="checkbox"/>	Preocupações	<input type="checkbox"/>	<input type="checkbox"/>	Náuseas
	<input type="checkbox"/>	<input type="checkbox"/>	Perda de interesse nas actividades diárias	<input type="checkbox"/>	<input type="checkbox"/>	Nariz congestionado/seco
	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Dores
	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Problemas sexuais
	<input type="checkbox"/>	<input type="checkbox"/>	<u>Problemas Espirituais/Religiosos</u>	<input type="checkbox"/>	<input type="checkbox"/>	Pele seca/comichões
	<input type="checkbox"/>	<input type="checkbox"/>	<u>Outros Problemas:</u>	<input type="checkbox"/>	<input type="checkbox"/>	Alergações do sono
						Formiguitos nas mãos e nos pés

The NCCN 2008 Distress Management Guideline. National Comprehensive Cancer Network. All rights reserved ©. To view the most recent version of the guidelines, go online www.nccn.org. Adaptado para português por S. Castro, Serviço de Psico-Oncologia, IPOFG, I.P.E., 2007 (Tradução autorizada pela NCCN).

Annex 3: Distress Thermometer

Annex 4: Socio-demographic and Clinical Questionnaire

Sujeito: _____

Consulta: 1^a 2^a

DADOS SOCIOBIOGRÁFICOS

Idade: _____ (anos)

Género: M F

Escolaridade: 4^o ano 6^o ano 9^o ano 12^o ano

Bacharelato/Licenciatura Mestrado/Doutoramento

Estado Civil: Solteiro Casado Viúvo União de facto Divorciado

Nº Filhos: _____

Estatuto Socioeconómico:

Até que ponto sente que tem dificuldades económicas?

1 2 3 4 5

DADOS CLÍNICOS

Diagnóstico: _____

Estadio: _____

Fase da Doença: _____

História de Tratamento:

Tratamento Prévio: Quimioterapia Radioterapia Cirurgia
 Nenhum

Tratamento Atual: Quimioterapia Radioterapia Cirurgia
 Nenhum

História Psicopatológica:

Diagnóstico Prévio: _____ Não

Diagnóstico Atual: _____ Não

Annex 5: Therapist's Adherence to Protocol Questionnaire

Instruções: Por favor, selecione o **grau de adesão específica a cada fase** do protocolo do PQ numa escala de cinco pontos em que 0 equivale a Adesão Nula, isto é, não seguir de todo os procedimentos indicados, e 5 a Adesão Total, ou seja, seguir rigorosamente as indicações do protocolo. Na coluna da direita por favor registre brevemente o motivo da alteração dos procedimentos.

Fase 1 Gerar os itens						Notas do/a terapeuta
Considerar: Como surgem os itens (espontaneamente ou através de um diálogo que se estrutura em torno das cinco áreas referidas no procedimento, i. é, humor, sintomas, relacionamento interpessoal, autoestima, atividade) e o número de itens levantados (<i>versus</i> o recomendado, i. é, 15)						
0	1	2	3	4	5	
Adesão Nula					Adesão Total	

Fase 2 Refinar / clarificar os itens						Notas do/a terapeuta
Considerar: Onde são redigidos?, por quem são redigidos?, qual o número médio de dificuldades definidas?						
0	1	2	3	4	5	
Adesão Nula					Adesão Total	

Fase 3 Hierarquização dos itens						Notas do/a terapeuta
Considerar: como são rerepresentadas as dificuldades ao paciente para as priorize?						
0	1	2	3	4	5	
Adesão Nula					Adesão Total	

Fase 4 Classificação quanto à intensidade de cada item						Notas do/a terapeuta
Considerar: Onde é apontada?, por quem é apontada?						
0	1	2	3	4	5	
Adesão Nula					Adesão Total	

Fase 5 Classificação quanto à duração de cada item						Notas do/a terapeuta
Considerar: E realizada?, onde é apontada?, por quem é apontada?						
0	1	2	3	4	5	
Adesão Nula					Adesão Total	

Fase 6 Construção do PQ						Notas do/a terapeuta
Considerar: A informação recolhida nas fases anteriores é registada num formulário em branco do PQ?						
0	1	2	3	4	5	
Adesão Nula					Adesão Total	

Por favor, indique o **grau de adesão global** aos procedimentos do PQ.

0	1	2	3	4	5
Adesão Nula					Adesão Total

Assinale com uma cruz a **periodicidade** com que tenciona aplicar o PQ.

Todas as sessões	De duas em duas	De três em três	Outra
------------------	-----------------	-----------------	-------

Obrigado pela sua colaboração.