

## Emotional Distress among Outpatient of Palliative Care Unit at Soetomo Hospitals Surabaya

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### Abstract

**Background:** Cancer patients are vulnerable for being emotional distress due to treatment, physical weakness and financial problems. Emotional distress could reduce their quality of life. Indeed, patients whom suffering extreme emotional distress will worsen their clinical prognosis.

**Aim:** To describe emotional distress of cancer outpatient at Palliative Care Unit of Soetomo Hospitals Surabaya Indonesia.

**Method:** A descriptive research with survey method on 30 outpatients in Palliative Care Unit of Soetomo General Hospitals. Data were taking on August 2016. Sampling method was using consecutive sampling. Distress Thermometer National Comprehensive Cancer Network (DT NCCN) 5 dimension problems: practical problem, emotional, family, spiritual and physical conditions, was used to measure 5 dimension problems (practical problem, emotional, family, spiritual and physical conditions). The Distress Scale is above 4.

**Results:** From 30 patient, 3 (10%) patient were man and the other 27 (90%) patient were woman. Among 21 patient (70%) patient were suffering distress emotion.

**Keywords:** Emotional; Distress; Cancer

### Introduction

When someone's under pressure (mental, physical, and emotional), they can experience psychological distress. There are many sources of distress, likes daily responsibility, routine event or unusual events. High level of distress emotional could develop mental and physical health problems [1].

One source of distress are being cancer patient. When they cannot manage changes because of cancer, they can be in distress. Cancer still being assumed of suffering, pain, and death. Emotional distress continuum ranging from common normal feeling of vulnerability, sadness and fear to problems that can become disabling anxiety, panic, social isolation and depression [2]. The stress because of diagnosis and the treatment of cancer can cause significant psychiatric morbidity [3].

NCCN describes emotional distress as multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer [2]. The Council of the Canadian Strategy for Cancer Control endorsed the concept of screening for emotional distress as the sixth vital sign, after the routinely assessed vital signs of pulse, respiration, blood pressure, temperature and pain [4].

Around 25% of cancer patient from variety studies has been reported significant distress. By using standardized psychiatric interview, the range of distressing cancer patient between 10 - 30% [2]. Anxiety and depression are prevalent among them. Its ranges 19 - 22% for depression and 12,9 - 16,5% for anxiety among patient whose newly diagnosis cancer [5].

In these study, we used Distress Thermometer for screening emotional distress among outpatient with cancer. This tools has been validated by International Comprehensive Cancer Network (ICCN). DT is practical tools that can be use in any condition especially if there were in busy conditions. It consist of 10 Scales from 0 (no distress) until 10 (severe distress). Patients whose mentioned the scale above or 4 are in distress. After they mention about the scale, they will list problems in the questionnaire [1,4].

Health professionals often fail to detect distress in their patients with cancer due to lack of confidence in assessing distress and using psychometric instruments and the limited time (Hughes). Indeed, distress for patient with cancer could worse their prognosis [1]. We hope by these research, the hospitals could develop the screening of emotional distress especially for patient whom they were newly diagnosed cancer, so they could reach better quality of life.

### Materials and Methods

This study was a quantitative research to analyze the emotional distress in 30 outpatient with cancer in Palliative Care Unit Soetomo general Hospitals. Sampling was non-random with consecutive methods. Participants were recruited belong to August 2016.

Participants were informed about the questionnaire by the researcher and they agreed participating these research by orally. During this study, there was no any special or adjuvant intervention for participants. On this research, we recruited 30 adult patient, during August 2016. The inclusion criteria were; they were registered as patient at Palliative care Unit Soetomo hospitals, they could understand and speak Indonesian language, and not in psychotic condition. The exclusion criteria were severe pain that impossible for them to answer the questionnaire.

We used DT scale by asking the participant. The reliability and validity of the questionnaire have been approved by the National Comprehensive Cancer Network (NCCN) and it is suggested to be used in different countries. Besides DT questionnaire, we also asked the participant about a demographic informations which should be done by the researchers. Besides that, there was a list problems in the questionnaire which consisted 5 sections (functional, family, emotional, religious and physical problems). Regarding those questions, the researchers tried to explain them considering the participants cultures, social conditions, religions and education levels.

### Result

From 30 participants, 90% (27 patients) were women and the another were man. Mean age of cancer patients were 53,7. The range age between 31 - 70 years. The average diagnosed cancer were 2,54 years. The earliest diagnosed cancer was 2 months, and the latest was twelve years. From the type of cancer, 13 patient (44%) was carcinoma service, 7 patients (23%) were carcinoma mamma, 3 patients (10%) were carcinoma nasopharynx and 7 patients (23%) were suffer the other cancer. On the table 1, we could see demographic information.

70 percent (21 patients) reported being distress ( $DT \geq 4$ ), while 30 percent (7 patients) didn't experience distress emotional ( $DT \text{ Score} \leq 3$ ). Most of our respondent were moeslem, and Javanese's tribe. The level education of most respondent were low educated. Only 26,67% (8 respondents) has a moderate level education. 29 respondents (96,67%) has low social economic status.

From the table 2, we could see that the highest means score DT happened for the patient who has diagnosed as cancer for 1 - 4 years. Indeed, 2 respondent whose has been suffering cancer for more than 4 years, has no emotional distress.

Variable	Patients (%)
<b>Gender</b>	
Women	27 (90%)
men	3 (10%)
<b>Marital Status</b>	
Married	23 (76,78%)
Divorced	4 (13,33%)
Single	3 (10%)
<b>Religion</b>	
Moeslem	29 (96,67%)
Non Moeslem	1 (3,33%)
<b>Tribe</b>	
Javanesee	20 (66,67%)
Madura	10 (33,33%)
<b>Place of domicile</b>	
Out of Surabaya	24 (80%)
Surabaya	6 (20%)
<b>Education level</b>	
Illeterate	2 (6,67%)
Elementary school	10 (33,33%)
Junior high school	10 (33,33%)
Senior high school	7 (23,33%)
Graduate	1 (3,33%)
<b>Average monthly income</b>	
< Rp 1.000.000	21 (70%)
< 1000.000 - 3000.000	8 (26,67%)
> 3.000.000	1 (3,33%)
<b>Type Cancer</b>	
Cervix	13 (43,33%)
Breast	7 (23,33%)
Nasofaring	3 (10%)
Ovarium	4 (13,33%)
Laring	1 (3,33%)
Eye Cancer	1 (3,33%)

**Table 1:** Demographic Characteristic of participants.

Time of Illness	N (Total resp Respondens)	Mean DT	Min-Max
< 1 years	4	5,25	3 - 10
1 - 2 years	15	6	2 - 10
3 - 4 years	9	6	1 - 10
> 4 years	2	1	1

**Table 2:** Characteristic time of illness and DT score.

In these research, we didn't ask about how the respondents did their physical activities. all of our respondents visited the hospitals by themselves without the aid of wheelchairs. Table 3 described the most problem of 70% respondent who had emotional distress.

Dimension		N (percentage)	
Functional Problems	Housing	6 (28,57)	
	Child care	6 (28,57)	
	Financial	12 (57,14)	
	Transportation	6 (28,57)	
	Work	3 (14,29)	
	Treatment decisions	2 (9,52)	
	Family Problems	Dealing with children	7 (33,33)
		Dealing with spouse	5(23,81)
Ability to have childrens		1(4,76)	
Family health issues		3 (14,29)	
Emotional Problems	Depression	16 (76,19)	
	Fears	5 (23,81)	
	Nervousness	4 (19,05)	
	Sadness	21(100)	
	Worry	20 (95,24)	
	Loss of interest in usual activities	8 (38,1)	
Spiritual Problems	Religion/ spiritual concern	2 (9,52)	
Physical problems	Appearance	5 (23,81)	
	Bathing/dressing	4(19,05)	
	Breathing	2 (9,52)	
	Urination	5(23,81)	
	Constipation	4 (19,52)	
	Diarhea	2 (9,52)	
	Eating	10 (47,62)	
	Fatigue	15 (71,43)	
	Feeling swollen	8 (38,10)	
	Getting around	14 (66,67)	
	Ingestion	8 (38,10)	
	Pain	21 (100)	
	Sexual	6 (28,57)	
	Sleep	9 (42,86)	

**Table 3:** Characteristic 5 dimensions problems of distress patients.

From the functional problems, Financials is the most problems for the respondents (57,14%). Dealing with children is the most problems in the dimension families problems (33,3%). In the dimension emotional problems, all of the respondent reported feel sadness. They also complained feeling worry (95,24%), and depression (76,19%).

2 respondents (9,52%) complained about spiritual problems. There are several complaints regarding about the dimensions of physical problems; pain (100%), fatigue (71,43%), getting around (66,67%) and eatings (47,62%).

## Discussion

Being diagnosed as cancer is very big stressor for almost people. In these study, we could see that two third respondents had emotional distress not only because of the cancer but also the psychosocial problems. This results seems different with the research of Saedi-Saedi in Iran, that's only about one-third respondent of breast cancer had emotional distress. Maybe because in our result not only breast cancer patients were recruited as our respondents. Nevertheless, it may happen from the discrepancy of their perception to be an healthy like before, and the reality of the treatment. Some patients also admitted to being disappointed, because despite having followed all the procedures, the cancer was not clear as their expectations (Bultz., *et al.* 2016).

Almost of our respondents are pre-elderly, whose their mental capacities has declined. They might felt difficult adjusting of cancer diagnosis. Moreover, the effectivities treatment for the cancer of pre elderly, is not as affective like an adult patient, so the symptom improvement of the cancer were less visible [6].

Financial is the most problems that has been concerned of the respondents. It might associated with the cost of living. In Indonesia, the insurance only recovering the specific treatment, but another cost of expenses like daily charge of boarding room for the caregiver, transportation, or the cost of the patient's need (like pampers, etc). Transportations is needed because most of them lives out of Surabaya. Besides, most of the respondent are from low middle economic statues. Having cancer, of course adding the financial burden for them. Financial problems can lead to increased financial burden which it can lead the low self-esteem, and a lower sense of control their lives [7]. From the research of Guay., *et al.* 2015, we know that patient with advance cancer susceptible to financial distress. they needs an extra cost to purchase a new clothes, supplements, nutritional diets, house care/child care [8].

One to third patients reported distress about dealing with children and spouse. With their children, almost patient felt worried about the future of their family. Respondent whose had children still in school, worried about the education. While pre-elderly respondent worried about inheritance. Some children refuse for taking responsibility about patients condition, instead they asked the inheritance. Pre-elderly respondent vulnerable to feel depression because of their heirs behavior that not taking care enough. This illness needs more support of the family members. They must learn a new skill and a new role to take responsibility of patients. Disruption of role functional and daily patterns of living could be happen, especially when they reorganize their routinity, and compensate in other ways of changing patients physical, emotional and psychological. The role change may become the most problems for family member [9].

With the spouse, unfulfilled sexual needs is the most problems. In our research, almost of the respondents are female cancer survivors (cervical cancer), surely that make them difficult to engage in sexual activities. If the spouse doesn't take care and understand this problems, it can disrupt the quality of marital relationship. Some studies highlighted that cancer survivors have serious problems like sexual disfunction, loss fertility, and fatigue. The most common cause of sexual dysfunction is pain during sexual intercourse that reported 44,8% women's. Emotional distress, relationship conflict also heightened the risk of sexual dysfunction (Pumo., *et al.* 2012).

From the emotion dimension, its shows that most of them also had a depression, sadness and worries. They told that they worried about the future after being cancer patients. They thought it may be a little opportunity to have long lasting life. Whereas, they have children that is still in school. They anticipate about the worse things, like treatment failure, which happen anytime. They means that although they had followed many of treatment procedure, but if the cancer were not disappears, its means that they never recovered. These result is same with the researches of Kasymjanova, that almost of the respondents shows depressions because of being cancer patients [4]. The life experience of being cancer survivors has important psychosocial implications that's impact their quality of life. Anxiety, depression, fear, affective disorder, and also cognitive disorder are very common in cancer survivor (Pumo., *et al.* 2012).

Two respondents reported that has spiritual problems, and both of them were a moslems. They were not only being made for the God, but also feeling guilty because of their limitation to do a worships. Because of the cancer, they experienced bleeding like menstruation, so they felt doubt about the chastity.

All respondents reported about pain. They told that pain limited their ability to move around. They felt uncomfortable, because they have to ask the caregiver to fulfill their needs. Uncontrollable pain might have been resulted from inadequate pain management, especially analgesic administration. In Surabaya prescribing an opioid for pain killer is still limited. There are a lot of multiple factor that can cause pain of cancer. It can involves inflammatory and neuropathic components, therefore, an adequate dose of adjuvant analgesic (e.g. opioid) may necessary to relive pain [10]. Gehdo (2006) said the cause of pain was cancer itself that press any other organs, bone, blood vessels or nerves. Assessment comprehensive and carefully is important for best treatment of the pain [11].

## Conclusion

Most of cancer respondents Soetomo Hospitals experiences emotional distress. Problems of emotional distress include practical, family, and emotionals. Its seems that cancer patients need to be observed the condition of their emotionals. DT NCCN can be used as a tools to measure distress emotionals.

## Suggestion

Screening of emotional distress for Cancers patient can be done to prevents the possibility of mental disorder. Patients with emotional distress needs for treatment holistically include psychiatric accompaniment. About pain that the most cause of distress emotionals in dimension physical, requiring management of pain adequately. Clinician can also encourage discussion about the psychosocial aspect of the cancer, so the more evaluation can be encourage by the social worker or medical teams.

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