Psychological distress and problem list among patients with advanced cancer: A comparative study of Indonesia and Taiwan

Nurul Huda

Universitas Riau

Malissa Kay Shaw

Taipei Medical University

Yen-Kuang Lin

Taipei Medical University

Wei-Zhen Yu

Taipei Medical University

Hsiuju Chang (✉ hsiju26@nycu.edu.tw)

National Yang Ming Chiao Tung University - Yangming Campus <https://orcid.org/0000-0002-8544-0712>

Research Article

Keywords: Advanced cancer, psychological distress, Problem list, Indonesia, Taiwan

Posted Date: November 29th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-945338/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Background

We assumed that patients in a country with lower economic development will have more psychological distress and problems than an economically stronger country. Therefore, the aims of this study were to determine whether advanced cancer patients in Indonesia have more psychological distress and experience more problems contributing to distress than a similar group of patients in Taiwan. We also examined the determinants of psychological distress.

Methods

We conducted a secondary data analysis comparing the data from 286 Indonesian and 70 Taiwanese participants, focusing on distress score and the Problem List (PL) of the Distress Thermometer. Descriptive analysis, Chi-Square test, independent t-test, One-way Anova and multiple linear regression with enter method were applied to analyse the data.

Results

Overall, more Indonesian respondents experienced distress and had more problems across all PL domains than Taiwanese participants. Being an early adult, having problems with childcare, housing and transportation were associated with higher distress while a higher depression score and having stage 4 cancer demonstrated lower distress among Indonesians. For Taiwanese respondents, appearance, bathing/dressing and pain determined psychological distress.

Conclusions

Differences in the healthcare system, economic level, culture, gender and age influenced the problems experienced by patients. Finding from our comparative study provide important insight into understanding distress and PL among ACPs in economically advanced countries compared with economically weak countries. Future collaboration to deliver interventions considering cultural and healthcare system differences between two countries should be developed

1 Introduction

Cancer is the leading cause of death in both developed and developing countries¹. However, the type of cancer diagnosed and the leading cause of cancer death vary across countries and depend on economic level, social development and people's lifestyles². For example, in low-middle income countries many patients have limited access to appropriate diagnosis and treatment while in countries with stronger

healthcare systems, greater access to early detection and high-quality treatment are improving survival rates³. These differences have created a gap in survival rates between countries.

Indonesia has had an upward trend in cancer incidence in the past decades. Cancer ranks among the ten most common causes of death and nearly 70% of cancer cases are diagnosed at an advanced stage. In addition, many unmet needs have been found among cancer patients and their family⁴. A report from The Economist Intelligence Unit (2015)⁵ showed that Indonesia ranked 53 of 87 countries in the quality of death index indicating that Indonesia scores poorly in providing cancer care. Although current official data is lacking, due to these conditions, advanced cancer patients (ACPs) in Indonesia are at higher risk of experiencing psychological distress. In comparison, Taiwan is a high-income country, where cancer is also a leading cause of death⁶. Despite a high incidence rate, the mortality rate is decreasing due to continual improvement in care⁷. Therefore, it is not surprising that Taiwan ranks 4th of 87 countries in the quality of death index⁵.

Since 2012, there has been an increase in advanced stage cancer diagnoses and advanced stage deaths⁸. Given the increase in cancer survivors, psychological wellbeing has become an important outcome of cancer care quality⁹. A common problem among ACPs is psychological distress. Distress can result from emotional and social changes brought on by cancer diagnosis, and effects of disease including physical burden and its treatment¹⁰. Unmanaged distress may result in numerous negative outcomes such as non-adherence to treatment, longer hospital stays, poorer quality of life (QOL) and lower survival rates^{11,12}. Therefore, identification and early treatment of distress are essential.

Identification of distress among ACPs, however, is still quite challenging which means distress goes underrecognized and, thus, undertreated¹³. Furthermore, many health systems in low- and middle-income countries are not well prepared for identifying and treating distress³. The National Cancer Comprehensive Network (NCCN)¹⁴ Distress Thermometer (DT) may be an ideal tool to address this. It has also been translated with acceptable psychometric properties into several common languages, spoken in both developed countries, such as using Mandarin (Taiwan), and developing countries, such as Bahasa (Indonesia)^{15,16}.

Limited research has studied distress in Taiwan and Indonesia, and in particular distress among ACPs has not been studied. Furthermore, comparative analyses that explore the differences in distress and problems that contribute to this distress between these two countries do not exist. The aim of this study was, therefore, to determine whether ACPs in Indonesia have more psychological distress and experience more problems associated with distress than a similar group of patients in Taiwan. Additionally, we examined the determinants of psychological distress including socio demographics and problems contributing to distress as indicated on the DT-Problem List. We assumed that patients with advanced cancer in Indonesia, a country with lower economic status, lower quality death index, limited access to healthcare professionals (HCPs) and the tendency for people not to seek medical assistance even in

advanced stages, would experience more psychological distress than patients in Taiwan, a country with higher income and better medical resources.

2 The Study

2.1 Design

A secondary data analysis research design was used, which merged data from two studies conducted in Indonesia¹⁷ and Taiwan. In Indonesia a cross sectional research design was implemented which aimed to explore the mediator of coping among patients with advanced cancer¹⁷. The study conducted in Taiwan used a randomized control trial research design to explore the effectiveness of navigator for a group of patients with cancer.

2.2 Participants

Inclusion and exclusion criteria for participants in the two countries were identical. The inclusion criteria were: (1) diagnosed with advanced cancer (stage 3 or 4 as checked in medical record by researcher), regardless of the type of cancer; (2) at least 18-years-old; (3) the ability to speak their national language. The exclusion criteria consisted of: (1) having a severe medical condition; (2) having a major psychiatric disorder as comorbidity; (3) being too ill to fill out the study questionnaires. Based on these criteria, we selected 286 out of 440 participants from the Indonesian sample and 78 out of 191 participants from the Taiwan sample.

2.3 Data collection

Data collection procedures in Indonesia are described in Huda et al. (2021)¹⁷. The study in Taiwan was conducted in a cancer center of a teaching hospital. Trained oncological nurses recruited eligible patients from outpatient departments. Part of the pre-test study variables were selected for this study. The two studies collected the same study variable of the DT and similar demographic and clinic characteristics. The two data sets were then analyzed by the first author who selected the cases that met the inclusion criteria.

2.4 Instruments

Background information form

The participants' demographic and clinical characteristics were obtained using sociodemographic and clinical characteristic questionnaires. The demographic data consisted of personal information: age, gender, ethnicity, religion, marital status, educational level, occupation and income level. The clinical characteristics include the type and stage of disease, time since diagnosis and current treatment.

Distress thermometer

Distress thermometer is a single item, self-report questionnaire developed by NCCN that measures psychological distress¹⁴. Patients rated their distress in the past week on an 11-point visual analog scale. Its scores range from 0 (no distress) to 10 (extreme distress). A cut off score ≥ 4 has been accepted by NCCN as an indication of distress. Both the Indonesia and Taiwanese versions of the DT have been validated^{15,16}. Afterwards, the patient was asked to fill the Problem List (PL) that accompanies the DT to check whether they experienced any of the problems listed during the previous 7 days. The PL describes the nature of problems which may cause distress. It consists of 36 problems grouped into 5 domains: practical, family, emotional, spiritual/religious and physical

2.5 Ethical considerations

For the Indonesian study ethical approval was granted by both the Ethical Review Board for Medicine and Health Research of the Faculty of Medicine, Universitas Riau (No 035/UN.19.5.1.1.8/UEPKK/2019) and by the Taipei Medical University-Joint Institutional Review Board (TMU-JIRB; No N201905001). The TMU-JIRB (No N201809031) approved the Taiwanese study. Written informed consent was signed by participants prior to study enrolment.

2.6 Data analysis

Statistical Package for Social Science (SPSS 22.0) was used for data analysis. We used percentages to determine the frequency of demographic and clinical characteristics of patient groups as well as the answers for each question in each PL domain. A Chi-square test was used to identify differences between the demographic, clinical characteristics and PL of both groups. To explore the association between demographic and clinical characteristic factors with distress, independent t-test and One-way Anova were applied. Furthermore, a multiple linear regression model using enter method was created to examine which variable best predicts the distress among ACPs from both countries. Covariables were introduced into the final model. All significant demographic factors and problems were included in the model. A *p* value of 0.05 was set as the level of significance.

3 Results

3.1 Demographic and clinical characteristics

The data of 286 (65%) patients with advanced cancer collected in an Indonesian referral hospital were compared with the data of 78 (41.2%) patients with advanced cancer in Taiwan. Table 1 shows the differences in the demographic data and clinical characteristics of both countries.

Table 1
Sociodemographic and Clinical Characteristics of Indonesian and Taiwanese Respondents and Distress Association.

	Indonesia % (n = 286),	Taiwan % (n = 78)	Significance ^a
Gender			
• Female	88.5	35.9	<0.001
• Male	11.5	64.1	
t test	-0.466 ^b	-0.165 ^b	
P value	0.658	0.869	
Age			
• Early Adults (18-35 years)	24.5	3.8	<0.001
• Middle Adults (36-55 years)	63.3	39.7	
• Elder Adults (> 55 years)	12.2	56.4	
• Mean (SD)	47.43 (11.35)	56.82(11.76)	
• Range	(18-80)	(21-93)	
F test	6.792 ^c	0.577 ^c	
P value	0.001	0.564	
Marital Status			
• Married	78.4	64.1	0.060
• Single	25.1	35.9	
t test	0.193 ^b	0.255 ^b	
P value	0.8473	0.800	
Education			
• Primary School	48.6	24.4	<0.001
• High School	48.3	35.9	
• College above	3.1	39.7	
Note: ^a Chi-Square test; ^b Independent t test; ^c Anova Test			
*The patient received a single type of therapy such as chemotherapy only.			
**The patient received more than one type of therapy such as chemotherapy and radiotherapy			

	Indonesia % (n = 286),	Taiwan % (n = 78)	Significance ^a
F test	6.792 ^c	1.515 ^c	
P value	0.001	0.256	
Job Status			
• Working	26.6	35.9	0.106
• Not Working	73.4	64.1	
t test	1.547 ^b	-0.704 ^b	
P value	0.123	0.483	
Income Category			
• Below Minimum Wage	22.7	27	0.438
• Similar & Above Minimum Wage	77.3	73	
t test	1.029 ^b	1.023 ^b	
P value	0.304	0.310	
Type of Cancer			
• Cancer in Reproductive System	76.2	33.6	< 0.001
• Cancer in Digestive System	6.6	35.9	
• Cancer in Respiratory System	2.4	16.7	
• Cancer in Urinary System	1.3	7.3	
• Cancer in Other System	13.6	6.4	
F test	0.733 ^c	0.809 ^c	
P value	0.570	0.524	
Stage of Disease			
• Stage 3	72	38	<0.001
• Stage 4	28	61	

Note: ^aChi-Square test; ^bIndependent t test; ^cAnova Test

*The patient received a single type of therapy such as chemotherapy only.

**The patient received more than one type of therapy such as chemotherapy and radiotherapy

	Indonesia % (n = 286),	Taiwan % (n = 78)	Significance ^a
t test	2.162 ^b	-1.303 ^b	
P value	0.031	0.197	
Time since Diagnosis			
• Less than and Similar to 6 Months	35.3	37.2	0.761
• More than 6 Months	64.7	62.8	
t test	1.350 ^b	0.154 ^b	
P value	0.178	0.878	
Type of Therapy			
• 1 Type of Therapy*	50.3	82.1	<0.001
• >1 Type of Therapy*	49.7	17.9	
t test	0.684 ^b	-0.682 ^b	
P value	0.495	0.498	
Distress			
Mean	4.74 (2.54)	3.00 (2.62)	
• Clinically Distressed	67.8	44.9	<0.001
• Not Clinically Distressed	32.2	55.1	
Note: ^a Chi-Square test; ^b Independent t test; ^c Anova Test			
*The patient received a single type of therapy such as chemotherapy only.			
**The patient received more than one type of therapy such as chemotherapy and radiotherapy			

Overall, more than 50% of both the Indonesian and Taiwanese patients were married, not working, and had an income level similar to or above the national minimum wage. Most of them had been diagnosed more than six months previously. The results also reported that Indonesian and Taiwanese respondents had different characteristics in regards to gender, educational level, stage of cancer and type of therapy. The differentiations were statistically significant (P value < 0.001). The ratio of women to men was disproportionate in both study groups. The majority of Indonesian respondents were females while most Taiwanese patients were male. Overall Indonesian respondents were younger than Taiwanese participants. Additionally, 3.1% of Indonesian patients had college level education or above compared with 39.7% of Taiwanese participants. Regarding the stage of disease, more than half of the Indonesian

patients had stage 3 cancer while half of the Taiwanese patients had stage 4 cancer. Of the Indonesian participants, two-thirds followed more than one treatment therapy opposed while two-thirds of Taiwanese patients received only one.

3.2 Distress and Problem List

Overall, more Indonesian respondents (67.8%) experienced distress than Taiwanese participants (44.9%). The statistical results showed significant differences ($p < 0.001$). The PL demonstrated that most Indonesian respondents had more problems across all domains than Taiwanese respondents. For the practical problems domain, more Indonesian respondents reported having problems with childcare, housing, insurances, transportation, work/school and treatment decisions than Taiwanese respondents. The gap in housing is particularly significant. Regarding the family domain, dealing with one's partner was the biggest problem for Indonesians while the family health issues was the most concerning problem among Taiwanese.

In the emotional problems domain, Indonesians reported depression, nervousness and sadness more often than Taiwanese. Interestingly, the domain spiritual/religious problems present the biggest gap among these two countries. In the physical problems domain, fatigue, fever, mouth sores, nausea, pain and tingling in feet differed significantly between Indonesian and Taiwanese participants where Indonesian respondents reported additional problems. Summary relationships of all problems between Indonesian and Taiwanese respondents are presented in Table 2.

Table 2. Problem List of Patients with Advanced Cancer

Practical Problems

	Indonesia	Taiwan	
Child Care			
• No	54.2	91.0	<0.001
• Yes	45.8	9.0	
Housing			
• No	48.3	96.2	<0.001
• Yes	51.7	3.8	
Insurance/Financial			
• No	62.6	85.9	<0.001
• Yes	37.4	14.1	
Transportation			
• No	60.5	88.5	<0.001
• Yes	39.5	11.5	
Work/School			
• No	62.6	85.9	<0.001
• Yes	37.4	14.1	
Treatment Decision			
• No	61.2	83.3	<0.001
• Yes	38.8	16.7	

Family Problems

	Indonesia	Taiwan	
Dealing with Children			
• No	58.4	92.3	<0.001
• Yes	41.6	7.7	
Dealing with Partner			
• No	55.2	94.9	<0.001
• Yes	44.8	5.1	
Ability to Have Children			
• No	63.3	97.3	<0.001
• Yes	36.6	2.6	
Family Health Issues			
• No	67.5	88.5	<0.001
• Yes	32.5	11.8	

Emotional Problems

	Indonesia	Taiwan	
Depression			
• No	61.2	82.1	<0.001
• Yes	38.8	17.9	
Fear			
• No	42.7	75.6	<0.001
• Yes	57.3	24.4	
Nervousness			
• No	49.7	75.6	<0.001
• Yes	50.3	24.4	
Sadness			
• No	45.1	74.4	<0.002
• Yes	54.9	25.6	
Worry			
• No	43.7	46.2	0.797
• Yes	56.3	53.8	
Loss of Interest in Activity			
• No	81.8	88.5	<0.222
• Yes	18.2	11.5	

Spiritual/Religious Problems

	Indonesia	Taiwan	
Religion			
• No	15.0	98.7	0.001
• Yes	85.0	1.3	

Physical Problems

	Indonesia	Taiwan	
Appearance			
• No	82.9	83.3	0.923
• Yes	17.1	16.7	
Bathing/Dressing			
• No	83.2	88.5	0.259
• Yes	16.8	11.5	
Breathing			
• No	78	87.2	0.072
• Yes	22	12.8	
Change in Urination			
• No	82.5	87.2	0.325
• Yes	17.5	12.8	
Constipation			
• No	80.1	84.6	0.364
• Yes	19.9	15.4	
Diarrhea			
• No	84.6	75.6	0.063
• Yes	15.4	24.4	
Eating			
• No	65.7	74.4	0.149
• Yes	34.3	25.6	
Fatigue			
• No	27.3	55.1	<0.001
• Yes	72.7	44.9	
Feeling Swollen			
• No	76.6	84.6	0.127
• Yes	23.4	15.4	
Fevers			

	Indonesia	Taiwan	
• No	77.3	92.3	<0.003
• Yes	22.7	7.7	
Getting Around			
• No	80.8	80.8	1.000
• Yes	19.2	19.2	
Indigestion			
• No	82.2	83.3	0.811
• Yes	17.8	16.7	
Memory Concentration			
• No	81.8	80.8	0.832
• Yes	18.2	19.2	
Mouth Sores			
• No	67.5	84.6	0.003
• Yes	32.5	15.4	
Nausea			
• No	58.4	76.9	0.003
• Yes	41.6	23.1	
Nose dry			
• No	82.9	79.5	0.490
• Yes	17.1	20.5	
Pain			
• No	46.9	67.9	0.001
• Yes	53.1	32.1	
Sexual			
• No	86.7	94.9	0.046
• Yes	13.3	5.1	
Skin Dry/Itchy			
• No	78.3	61.5	0.003

	Indonesia	Taiwan	
• Yes	21.7	38.5	
Sleep			
• No	55.6	57.7	0.741
• Yes	44.4	42.3	
Tingling in Foot			
• No	58	76.9	0.002
• Yes	42	23.1	

3.3 Sociodemographic and clinical characteristics associated with coping strategies

Summary relationships of demographic variables and clinical characteristics with distress are showed in Table 1. There is a significant relationship between age and distress among ACPs in Indonesia ($F=6.79$ $p=0.001$). A significant relationship was also demonstrated between the time of diagnosis and distress. Patients who had stage 3 cancer had higher distress than patients who had stage 4. However, no significant relationships were found between demographic and clinical characteristics among Taiwanese's respondents.

3.4 Determinants of Distress between Indonesian and Taiwanese Respondents

Table 3 shows the determinants of distress between Indonesia and Taiwanese respondents. The results of multiple linear regression revealed that early adults, stage 4, childcare, housing, transportation, and depression influenced psychological distress among ACPs in Indonesia. Being an early adult ($\beta = 1.16$; 95% CI [1.39, 3.14], $p=0.001$), having problems with childcare ($\beta = 1.15$; 95% CI [0.20, 2.11], $p=0.01$), housing ($\beta = 0.17$; 95% CI [0.01, 1.41], $p=0.044$) and transportation ($\beta = 2.07$; 95% CI [0.54, 3.60], $p=0.008$) were associated with higher distress. In contrast, patients who had a higher depression score ($\beta=-1.23$; 95% CI [-2.46, -0.006], $p=0.04$) and had stage 4 cancer ($\beta=-0.77$; 95% CI [-1.38, -0.15], $p=0.015$) demonstrated lower distress. For Taiwanese respondents, appearance, bathing/dressing and pain determined psychological distress. Results showed that having problems with bathing and dressing was associated with higher distress ($\beta = 3.78$; 95% CI [1.54, 6.03], $p=0.04$). Additionally, patients who suffered more pain had higher distress ($\beta = 2.96$; 95% CI [1.09, 4.81], $p=0.003$). Contradictory, patients who had problems with appearance had lower distress ($\beta=-2.14$; 95% CI [-4.22, -0.06], $p=0.04$).

Table 3
Determinants of Psychological Distress among Advanced Cancer Indonesian and Taiwanese Respondents

Characteristic ^a	b	t value	p value
Psychological distress among Indonesian patients with advanced cancer			
Early adults	1.16	3.31	<0.001
Stages of disease (stage 4)	-0.77	-2.45	0.015
Childcare	1.15	2.38	0.018
Housing	0.17	2.02	0.044
Transportation	2.07	2.69	0.008
Depression	-1.23	-1.98	0.049
R ² =32.2; F= 2.95; P value = < 0.001			
Psychological distress among Taiwanese patients with advanced cancer			
Appearances	-2.14	-2.09	0.043
Bathing and Dressing	3.78	1.12	0.002
Pain	2.90	3.21	0.003
R ² =74.61; F= 2.93; P value = < 0.001			
^a Only statistically significant characteristics are displayed in the table			

4 Discussion

We conducted a comparative study among Indonesian and Taiwanese patients with advanced cancer to compare psychological distress and explore determinants of this distress between the two countries. Overall, we found that ACPs in Indonesia have higher distress than Taiwanese patients. Indonesian patients also reported more problems in most of the PL domains. These findings correspond with previous findings^{15,16}. Such differences may result from more needs going unmet as has been found among ACPs in lower economic level countries as compared to stronger economic countries¹⁸. However, in our study it is worth noting that these differences may also be related to gender differences, as most Indonesian respondents were female. Women seem more willing to show their distress while men tend to be more reluctant¹⁹. Thus, women are more likely to have concordant screening results of DT¹⁵.

This study's results highlight that the prevalence of most problems were higher among Indonesian than Taiwanese patients. Housing and childcare problems were the top two practical problems among Indonesian participants, while 5% of Taiwanese patients reported these problems. This may reflection age

differences between the two countries as almost half of the Indonesian respondents were in the young- and middle-age groups. Pangestu et al. (2018)²⁰ found that over 90% of cancer patients in Indonesia suffer financial hardships due to their disease. Despite the availability of national health insurance, the cost of cancer treatment in Indonesia remains high often creating financial difficulties. Hence, it is not surprising that most Indonesian participants had housing problems. The higher rate of childcare problems reported by Indonesian respondents may relate to young- and middle-aged adults in Indonesia often have dependent children. Having advanced cancer puts pressure on them as their illness impacts their parental role, a predisposing factor to distress among parents with advanced cancer²¹. Additionally, most Indonesian respondents in this study were woman. As woman, compared to men, spend more time on parenting, housework and managing family care²² it is reasonable that childcare concerns contribute to distress among our sample. Contrarily, housing and childcare were not common sources of distress for Taiwanese participants. This may result from most Taiwanese participants being male and in the elderly adult group. Most elderly adults already have stable lives and are financially secure. Consequently, housing generally is not a problem and children would not still be dependent on them.

In relation to family problems, dealing with one's partner was the primary concern, possibly due to most Indonesian respondents being middle-aged women who suffered from cancer in the reproductive system. Diagnosis of advanced cancer and the following treatment have negative effects on the sexual, psychological and social functioning of patients, which may negatively impact their relationship with their partner²³. In comparison, the main concern in the family domain among Taiwanese participants were family health issues. This may be connected to the advanced age of most Taiwanese participants and their concerns for other aging family members. Unsurprisingly, the present study found that most emotional problems have significant difference between the two countries. Komariah et al.'s (2021)²⁴ study on the needs of ACPs in Indonesia showed that psychological support was the second unmet need ranked by patients. Lack of psychological support will lead to emotional problems. Unfortunately, the screening and referral system for distress has not been well established in Indonesia. The overload of HCPs limits patient-staff interactions, further restricting the ability for patients' emotional problems to be adequately screened²⁵. The Taiwanese healthcare context is quite different. A recent survey suggested that cancer patients in Taiwan have good care experiences²⁶.

The spiritual/religious domain presented the biggest gap between Indonesian and Taiwanese participants. Religion is fundamental in most Indonesians' lives, therefore, they try their best to sustain their religious practices until their death²⁷. However, having advanced cancer may limit their ability to perform certain practices. Central spiritual needs for Indonesian Muslim cancer patients, such as praying five times a day, were identified as the most important needs one could not meet²⁸. Not fulfilling spiritual needs negatively effects emotional wellbeing since spirituality is positively and significantly related to emotional wellbeing²⁹. The religious context is quite different in Taiwan, where beliefs have been influenced by Confucianism, Taoism and Buddhism. Many Taiwanese believe that suffering, including having advanced cancer, is a universal human experience. Considering this, Taiwanese strive to do as much goodness as possible to overcome bad karma and be led to a better afterlife³⁰.

Although Indonesia and Taiwan are different culturally and in terms of economic development, our results show that most physical problems are similar and comparable except for fatigue, pain, nausea and mouth sores. However, fatigue and pain were still the most often reported physical problems among both participant groups and at comparable rates to other studies. Patients with advanced cancer commonly experience fatigue and consider it a disabling symptom since it can persist for years after treatment³¹. Fatigue was reported by 72.7% and 44.9% for Indonesian and Taiwanese patients respectively. These rates are similar to the prevalence of fatigue among ACPs around the world which ranged from 43–64%, the higher rates are more prevalent among female patients, specifically those with gynaecological cancer³². Therefore, it is not surprising that the incidence of fatigue was higher among Indonesian respondents who were commonly female and suffered from gynaecological cancer.

Pain severity was significantly related with psychological distress among ACPs³³. Although Taiwanese patients were satisfied with their physicians in terms of pain control, treatment of cancer pain is still suboptimal as more than 70% of physicians do not prescribe analgesics based on their patient's current status³⁴. Interestingly, Indonesian patients experienced more pain in this study. Incompetent assessment of pain, doctors' and patients' reluctance to use opioids due to addiction fears and the difficulties of obtaining morphine due to complicated and tight regulation have been identified as reasons for inadequate pain management in Indonesia³⁵. Indonesian patients more often mentioned having mouth sores and nausea than Taiwanese patients. In this study, most Indonesian patients followed more than one treatment, which may cause worse side effects and put them at risk of malnutrition. Mouth sores and decreased food intake have been reported as severe enough to cause nutrient deficiency among ACPs, and have been associated with distress³⁶.

In this study, we surprisingly found that depression was associated with lower distress among Indonesian respondents. This corresponds with Chew et al.'s (2017)³⁷ longitudinal study that found depression could alter distress in chronic diseases. Possibly, patients who had depression had already constructed their coping strategy which helps them deal with their diseases. These strategies may later be useful to combat further distress³⁷. Inconsistent with previous research³⁸, our research found patients in stage 4 had lower distress. The differences in these findings might result from most Indonesian respondents having been diagnosed with reproductive cancer, particularly breast cancer. Similar to previous research, presence of metastases (stage 4) was associated with emotional distress except for breast cancer patients³⁹. Transportation was also a source of distress for Indonesian participants. Indonesia consists of thousands of islands. Frequently patients have to rent private transportation and travel for long distances to access HCPs. Thus, patients may experience physical discomfort, time consumption and high costs which contribute to psychological distress⁴⁰.

A noteworthy finding of this study was that only physical problems accounted for a significant amount of variance in distress among Taiwanese participants. Contrarily, Indonesians reported practical and emotional problems as determinant factors for distress. This aligns with Peters and colleagues' (2020)³⁸ study who found that younger people more frequently reported practical and emotional problems.

Surprisingly, in this study, we also found that Taiwanese patients who had problems with appearance had lower distress scores. As most of the Taiwanese participants were male, this may be largely influenced by gender. Since males are more focused on body function than body appearance, they will have more distress when their body malfunctions⁴¹.

Finding from our comparative study provide important insight into understanding distress and PL among ACPs in Indonesia and Taiwan. Future collaboration to deliver interventions considering cultural and healthcare system differences between two countries should be developed. Furthermore, collaborated research should incorporate multiple research sites in each country and larger sample sizes into longitudinal research designs to enhance the generalizability of study results.

4.1 Limitations

This study has several limitations. Differences reported by the PL may have been influenced by the sample sizes, type of cancer, treatment and age of respondents, aspects that we did not explore. Specific attention to these aspects may provide additional data enabling better interpretation of the results reported here. Moreover, distress sources were assessed using dichotomous (yes/no) answers, prohibiting information on variation of symptom severity that might impact the level of distress being explored. Finally, this study did not account for co-morbidities or certain lifestyles that may have influenced distress sources. Hence, caution must be applied when generalizing these findings.

5 Conclusions

To the best of our knowledge, this is the first study to compare distress and its PL between ACPs in Indonesia and Taiwan. The results of this study primarily highlight differences of distress sources between patients in Indonesia and Taiwan. As predicted, Indonesian patients tend to experience more problems than Taiwanese, and spiritual/religious problems present the biggest gap among these two countries. Despite these differences, most physical problems did not differ significantly. These similarities contradict our hypothesis, possibly because physical problems among ACPs generally do not differ considerably. Furthermore, in both countries, pain and fatigue had the highest prevalence in the physical domain. This suggests important challenges for improving quality of care in both countries, such as amending pain control and fatigue management regulations. Notwithstanding these similarities, spiritual needs require increased professional attention among Indonesian patients in order to manage their distress and increasing comfort.

Declarations

Acknowledgements:

None.

Role of Funding.

This work was supported by the Ministry of Science and Technology Taiwan (MOST). Grant number: 108-6001-006-300. Hsiu Ju Chang is the grant recipient.

Conflicts of Interest.

All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

Ethics of Approval :

Ethical approval was granted by both the Ethical Review Board for Medicine and Health Research of the Faculty of Medicine Universitas Riau (No 035/UN.19.5.1.1.8/UEPKK/2019) and the Taipei Medical University-Joint Institutional Review Board (No N201905001) for the Indonesian study. The Taipei Medical University-Joint Institutional Review Board (No N201809031) approved the Taiwanese study.

Consent to Participate.

Informed consent was obtained from all individual participants included in the two studies.

Consent for Publication:

The participants has consented to the submission of the case report to the journal.

Availability of Data and Material

The data that support the findings of this study are available from the corresponding author upon request.

Authors' Contribution

Study Design: Nurul Huda, Hsiu Ju Chang

Analysis and interpretation of data: Nurul Huda, Hsiu Ju Chang, Malissa Kay Shaw, Yen-Kuan Ling, Wei-Zhen, Yu

Drafting of the manuscript: Nurul Huda, Hsiu Ju Chang, Malissa Kay Shaw, Yen-Kuan Ling, Wei-Zhen, Yu

Critical revision of the manuscript: Nurul Huda, Hsiu Ju Chang, Malissa Kay Shaw

Approval of the final version for publication: All authors

References

1. Sung H, Ferlay J, Siegel RL et al (2021) Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA Cancer J Clin 71(3):209–249.

2. United Nations Development Programme (UNDP). Beyond Income, Beyond Averages, Beyond Today: Inequalities in Human Development in the 21st Century. Human Development Report. 2019. <http://hdr.undp.org/sites/default/files/hdr2019.pdf> (accessed 25 November 2020)
3. World Health Organization (2021) Cancer. https://www.who.int/health-topics/cancer#tab=tab_1 (accessed 8 June 2021)
4. Witjaksono M, Sutandiyo N, Suardi DR (2014) Regional support for palliative care in Indonesia. https://ehospice.com/international_posts/regional-support-for-palliative-care-in-indonesia/ (accessed 29 June 2021)
5. The Economist Intelligence Unit (2015) Quality of Death Index. 2015 <http://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index> (accessed 30 March 2020)
6. Taiwan Cancer Registry. The age standardized incidence rate of cancers in Taiwan (2017) <http://tcr.cph.ntu.edu.tw/main.php?Page=A5B2> (accessed 22 Marc 2020)
7. Kuo CN, Liao YM, Kuo LN, Tsai HJ, Chang WC, Yen Y (2020) Cancers in Taiwan: Practical insight from epidemiology, treatments, biomarkers, and cost. *J Formos Med Assoc* 119(12):1731–1741. doi:10.1016/j.jfma.2019.08.023
8. Fedewa SA, Ma J, Jemal A (2020) Response to Lehrer and Rheinstein. *J Natl Cancer Inst* 112(10):1069–1070. doi:10.1093/jnci/djaa093
9. Riba MB, Donovan KA, Andersen B et al (2019) Distress Management, Version 3.2019, NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw* 17(10):1229–1249. <https://doi.org/10.6004/jnccn.2019.0048>
10. Howell D, Olsen K (2011) Distress-the 6th vital sign. *Curr Oncol* 18(5):208–210. <https://doi.org/10.3747/co.v18i5.790>
11. Lin C, Clark R, Tu P et al (2017) Breast cancer oral anti-cancer medication adherence: a systematic review of psychosocial motivators and barriers. *Breast Cancer Res Treat* 165(2):247–260. <https://doi.org/10.1007/s10549-017-4317-2>
12. Pir WF, Greer JA, Traeger L et al (2012) Depression and survival in metastatic non-small-cell lung cancer: effects of early palliative care. *J Clin Oncol* 30(12):1310–1315. <https://doi.org/10.1200/JCO.2011.38.3166>
13. Fallowfield L, Ratcliffe D, Jenkins V et al (2001) Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer* 84(8):1011–1015. <https://doi.org/10.1054/bjoc.2001.1724>
14. National Comprehensive Cancer Network. NCCN distress thermometer and problem list for patients (version 2. 2020) 2020. https://www.nccn.org/docs/default-source/patient-resources/nccn_distress_thermometer.pdf?sfvrsn=ef1df1a2_4 (accessed 11 December 2020)
15. Chiou YJ, Lee CY, Li SH et al (2017) Screening for Psychologic Distress in Taiwanese Cancer Inpatients Using the National Comprehensive Cancer Network Distress Thermometer: The Effects of

- Patients' Sex and Chemotherapy Experience. *Psychosomatics* 58(5):496–505.
<https://doi.org/10.1016/j.psych.2017.03.016>
16. Iskandarsyah A, de Klerk C, Suardi DR et al (2013) The Distress Thermometer and its validity: a first psychometric study in Indonesian women with breast cancer. *PloS one* 8(2):e56353.
<https://doi.org/10.1371/journal.pone.0056353>
 17. Huda N, Yun-Yen, Deli H et al (2021) Mediation of Coping Strategies among Patients with Advanced Cancer. *Clin Nurs Res* 10547738211003276 Advance online publication.
<https://doi.org/10.1177/10547738211003276>
 18. Effendy C, Vissers K, Tejawinata S et al (2015) Dealing with Symptoms and Issues of Hospitalized Patients with Cancer in Indonesia: The Role of Families, Nurses, and Physicians. *Pain Pract* 15:441–446. <https://doi.org/10.1111/papr.12203>
 19. Barrett LF, Bliss-Moreau E (2009) She's emotional. He's having a bad day: Attributional explanations for emotion stereotypes. *Emotion* 9(5):649–658. <https://doi.org/10.1037/a0016821>
 20. Pangestu S, Karnadi EB. Financial toxicity in Indonesian cancer patients and survivors: How it affects risk attitude, *Cogent Med.* 5,1. 2018. <https://doi.org/10.1080/2331205X.2018.1525887>
 21. Park EM, Deal AM, Check DK et al (2016) Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psychooncology* 25(8):942–948.
<https://doi.org/10.1002/pon.3935>
 22. Craig L (2006) Does Father Care Mean Fathers Share? A Comparison of How Mothers and Fathers in Intact Families Spend Time with Children. *Gend* 20(2):259–281.
<https://doi.org/10.1177/0891243205285212>
 23. Iżycki D, Woźniak K, Iżycka N (2016) Consequences of gynecological cancer in patients and their partners from the sexual and psychological perspective. *Prz Menopauzalny* 15(2):112–116.
<https://doi.org/10.5114/pm.2016.61194>
 24. Komariah M, Rahayuwati L, Fitria N et al (2021) Need Assessment on Patients with Advanced Stage Cancer. *EJMCM* 8(2):974–985
 25. Abrahamson K, Durham M, Fox R (2010) Managing the unmet psychosocial and information needs of patients with cancer. *Patient Intell* 2:45–52. <https://doi.org/10.2147/pi.s9442>
 26. Yu TH, Chung KP, Tung YC, Tsai HY (2018) Insight into Patients' Experiences of Cancer Care in Taiwan: An Instrument Translation and Cross-Cultural Adaptation Study. *Int J Environ Res Public Health* 15(8):1772. <https://doi.org/10.3390/ijerph15081772>
 27. Rochmawati E, Wiechula R, Cameron K (2018) Centrality of spirituality/religion in the culture of palliative care service in Indonesia: An ethnographic study. *Nurs Health Sci* 20(2):231–237.
<https://doi.org/10.1111/nhs.12407>
 28. Sastra L, Büssing A, Chen CH et al (2021) Spiritual Needs and Influencing Factors of Indonesian Muslims with Cancer During Hospitalization. *J Transcult Nurs* 32(3):212–220.
<https://doi.org/10.1177/1043659620908926>

29. Nuraini T, Andrijono A, Irawaty D et al (2018) Spirituality-focused palliative care to improve Indonesian breast cancer patient comfort. *Indian J Palliat Care* 24(2):196–201.
https://doi.org/10.4103/IJPC.IJPC_5_18
30. Hsiao SM, Gau ML, Ingleton C et al (2011) An exploration of spiritual needs of Taiwanese patients with advanced cancer during the therapeutic processes. *J Clin Nurs* 20(7-8):950–959.
<https://doi.org/10.1111/j.1365-2702.2010.03278.x>
31. Fabi A, Bhargava R, Fatigoni S et al (2020) Cancer-related fatigue: ESMO Clinical Practice Guidelines for diagnosis and treatment. *Ann Oncol* 31(6):713–723.
<https://doi.org/10.1016/j.annonc.2020.02.016>
32. Al Maqbali M, Al Sinani M, Al Naamani Z et al (2021) Prevalence of Fatigue in Patients with Cancer: A Systematic Review and Meta-Analysis. *J Pain Symptom Manage* 61(1):167–189.e114.
<https://doi.org/10.1016/j.jpainsymman.2020.07.037>
33. Mystakidou K, Tsilika E, Parpa E et al (2006) Psychological distress of patients with advanced cancer: influence and contribution of pain severity and pain interference. *Cancer Nurs* 29(5):400–405. <https://doi.org/10.1097/00002820-200609000-00009>
34. Rau KM, Chen JS, Wu HB et al (2017) Cancer-related pain: a nationwide survey of patients' treatment modification and satisfaction in Taiwan. *Jpn J Clin Oncol* 47(11):1060–1065.
<https://doi.org/10.1093/jjco/hyx124>
35. Setiabudy R, Irawan C, Sudoyo AW (2015) Opioid use in cancer management in Indonesia: A call for attention. *Acta Med Indones* 47(3):244–250
36. Ma X, Zhang J, Zhong W et al (2014) The diagnostic role of a short screening tool—the distress thermometer: a meta-analysis. *Support Care Cancer* 22(7):1741–1755.
<https://doi.org/10.1007/s00520-014-2143-1>
37. Chew BH, Vos RC, Stellato RK et al (2017) Diabetes-Related Distress and Depressive Symptoms Are Not Merely Negative over a 3-Year Period in Malaysian Adults with Type 2 Diabetes Mellitus Receiving Regular Primary Diabetes Care. *Front Psychol* 17(8):1834. doi 10.3389/fpsyg.2017.01834
38. Peters L, Brederecke J, Franzke A et al (2020) Psychological Distress in a Sample of Inpatients with Mixed Cancer: A Cross-Sectional Study of Routine Clinical Data. *Front Psychol* 11:591771.
<https://doi.org/10.3389/fpsyg.2020.591771>
39. Vodermaier A, Linden W, MacKenzie R et al (2011) Disease stage predicts post-diagnosis anxiety and depression only in some types of cancer. *Br J Cancer* 105:1814–1817.
<https://doi.org/10.1038/bjc.2011.503>
40. Ascencio-Huertas L, Allende-Pérez SR, Pastrana T (2021) Associated factors of distress in patients with advanced cancer: A retrospective study. *Palliat Support Care* 19(4):447–456.
<https://doi.org/10.1017/S1478951520001066>
41. Halliwell E, Dittmar H (2003) A qualitative investigation of women's and men's body image concerns and their attitudes toward aging. *Sex Roles* 49(11-12):675–684.
<http://doi.org/10.1023/B:SERS.0000003137.71080.97>