

# The Relationship Between Illness Acceptance, Cancer-Related Complaints and Psychological Distresses Among Malaysian Cancer Patients

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## Abstract

**Aim:** The present study investigated the relationship between psychological problems, illness acceptance and cancer-related complaints among Malaysian cancer patients. **Methods:** One hundred and six cancer patients were recruited and were requested to complete validated self-reported questionnaires that measured their psychological distresses, sleep quality, pain, fatigue and illness acceptance. **Results:** There was a significant relationship between cancer-related symptoms, illness acceptance and psychological distresses commonly experienced by local cancer patients ( $p < 0.05$ ). **Conclusion:** Malaysian cancer patients with more cancer-related complaints reported a higher level of psychological distresses and poorer illness acceptance. Increased level of illness acceptance was suggested in managing cancer patients with psychological distresses and cancer-related complaints.

**Keywords:** cancer, illness acceptance, Malaysian, psychological distresses

## INTRODUCTION

It is estimated that cancer cases in Asia will reach 10.6 million by the year 2030 (Ferlay et al., 2010). Most of the cancer patients reported that they have suffered from physical, social, psychological issues such as depression, anxiety and the side effect of the treatment (Charalambous et al., 2016). Treatment side effect such as poor sleep quality, cancer pain and cancer-related fatigue would be major medical issues with a pooled prevalence rate of over 50% for all cancer types (R Sankaranarayanan, 2011; Rengaswamy Sankaranarayanan et al., 2010). However, overall 5-year survival rates in Asia were less than 50% due to high defaulted cases from modern treatment and late cancer diagnosis (R Sankaranarayanan, 2011; Rengaswamy Sankaranarayanan et al., 2010). One of the reasons for high defaulted cases was the fear or ineffective side effect management and lack of psychological preparation for the treatment (Farooqui et al., 2011; A. W. Group et al., 2015; Chong Guan Ng et al., 2017).

The level of illness acceptance would influence the strategy adopted to cope with cancer. Czerw and colleagues showed with higher illness acceptance, cancer patients would have lower anxiety level and a feeling of hopelessness and better treatment outcomes (Czerw, Religioni, Deptala, & Fronczak, 2017). With a higher level acceptable of illness, this would enable an objective evaluation of one's own health status, and subsequently, patients were motivated to cope with the disease (Al-Azri, Al-Awisi, & Al-Moundhri, 2009). A qualitative study was conducted to investigate Malaysian cancer patients' perspective toward their cancer and its treatment (Farooqui et al., 2011). Most of the cancer patients who have spiritual supports appeared to have an effective way to cope with psychological distress (G. C. Ng, Mohamed, Sulaiman, & Zainal, 2017). In some cases, Malaysian

cancer patients defaulted from proven cancer treatments were due to the severity of side effects such as cancer-related fatigue, higher pain intensity, appearance changes and some cases defaulted was due to lack of motivation and acceptance of their illness (Chan & Ismail, 2014; Farooqui et al., 2011). Their psychological distress was under-reported and largely ignored by the patients.

The prevalence of depression was 12.5–31% and the prevalence of anxiety was 16–31.7% among Malaysian cancer patients (Hassan et al., 2015; Chong Guan Ng et al., 2017; G. C. Ng et al., 2017). Cancer patients exhibited a high prevalence of psychological distresses experienced uncertainty and worries about the future and the success of treatment that subsequently led to a clinical level of depressive and anxiety symptoms as well as acute stress level (Sharif, 2017). A cancer diagnosis would perceive as a severe stressor by the distress that patients feel even years after treatment (Deimling, Kahana, Bowman, & Schaefer, 2002). Most of the highly anxious and stressed cancer patients experienced fear of physical suffering (Chong Guan Ng et al., 2017; Sharif, 2017). Depressed cancer patients were less proactive in seeking treatment, longer recovery times and poorer outcomes (Charalambous et al., 2016). Most of them were lack of motivation, poor concentration and feeling of guilt or shame, loss of interests and appeared to be withdrawal from others (Hassan et al., 2015). Cancer patients with psychological distressed were questioned about their ability to cope with the treatment and influence the adopted strategy of coping. These psychological distresses have remarkably deleterious effects on quality of life (Tung et al., 2016). Most of the postsurgical cancer patients reported there were disturbances and limitations in their daily functioning (Gillis et al., 2014) and psychological distresses such as depression and anxiety (A. S. Group, 2017). With regards to this issue, clinicians and researchers suggested pre-operative intervention that would enhance patient's psychological wellbeing and increase functional recovery process to be conducted before surgery or other intensive medical procedures (Santa Mina et al., 2014). Cancer patients involved in the prehabilitation program reported higher physiological and functional capacity as compared with those prescribed rehabilitation only (Santa Mina et al., 2014).

Cancer patients are particularly distressing before receiving any recommended cancer treatment (Andersen et al., 2008; A. S. Group, 2017). The prehabilitation approach should apply to all cancer patients receiving all types of treatment modalities. However, to date, limited number of studies were found illustrating the cancer-related complaints and psychological distresses suffered by the Malaysian cancer patients in which limited baseline data found for further evaluation and prevention management. Patients who received cancer treatment regardless of their cancer type were recruited as most of the studies were only focused on one specific cancer type. This was lacking generalizability and increased the difficulty level for the authorities and/or clinicians to design an intervention program that would be feasible to be used in the busy oncology clinic. The present study aimed to investigate the psychological problems suffered by the Malaysian cancer patients in which hope to provide some baseline data for the future pre- and postrehabilitation program that tailor local patients' needs. It was hypothesized that the prevalence of depressive and anxiety symptoms as well as stress level would be high among cancer patients. There would be a significant relationship between cancer-related complaints, illness acceptance and psychological symptoms with types of cancer.

## **METHOD**

### **Participants**

The participants recruited in the study aged between 32 and 82 received cancer treatment at Universiti Kebangsaan Malaysia Medical Centre, Hospital Canselor Tunku Muhriz (UKMMC). All

participants have an official diagnosis of cancer from the doctors. They were able to communicate in English or Malay language. Patients who were diagnosed with other diseases or hemodynamically unstable and dependent on opiates were not included in the present study. There was no missing value in the present study. In total there were 106 participants included in the present data analysis. Their age ranged between 32 and 82 years old (mean [M]: 61.6, standard deviation [SD]: 11.69) and it was normally distributed with a kurtosis (0.142) close to 0. Twenty-two percent of the participants were newly diagnosed cancer patients and 78% of them have their cancer diagnosis more than a year. Table 1 described detail demographic characteristics including their age, gender, ethnicity and cancer diagnosis of the present participants.

### **Data collection procedures**

Participants were recruited based on simple random sampling. Participants would be referred by the oncologists and their written consent form was a prerequisite for participating. Questionnaires were used to gather their sociodemographic information and other related information would be collected. Other information including types of cancer, duration of being diagnosed with cancer, cancer acceptance, cancer-related symptoms such as their sleeping quality, pain and fatigue were gathered through a face-to-face individual interview.

This study was approved by the ethics committees, Faculty of Health Sciences, Universiti Kebangsaan Malaysia with reference code JEP-2017-571. After obtaining the ethics approval, the head of the Oncology Department at PPUKM was contacted to obtain agreement and arrangement for data collection.

### **Measures**

#### ***Medical & sociodemographic characteristic***

The basic demographic variables such as age, gender and ethnicity were collected. Additional questions regarding patients' cancer diagnosis, duration of having a cancer diagnosis, cancer treatment patient had received were asked too.

#### ***Psychological distresses***

Depression, Anxiety and Stress Scale-21 items (DASS-21) is a self-report screening tool designed to measure the emotional states of depression, anxiety and stress (Lovibond & Lovibond, 1995). It comprises three subscales which are depression, anxiety and stress. Each of the three subscales contains seven items. Participants rated the response to the items on a scale from 0 to 3. A total score of each subscale was summed and multiplied by 2 to calculate the final score. The Malay version of DASS was used (Musa, Ramli, Abdullah, & Sarkarsi, 2011). For the full sample in the present study, the Cronbach's  $\alpha$  of this DASS-21 was 0.9.

#### ***Sleep quality***

The Pittsburgh Sleep Quality Index is a 19-item self-report questionnaire that used to assess the sleep qualities and quantity (Buysse, Reynolds III, Monk, Berman, & Kupfer, 1989). Participants reported their sleeping time and have to rate the quality of their sleep on a range of 0–3 points, with 0 indicates no difficulty while a score of 3 indicates severe difficulty. For the full sample in the present study, the Cronbach's  $\alpha$  of Pittsburgh Sleep Quality Index was 0.65.

#### ***Pain intensity***

The patient pain questionnaire is a 16-item self-report questionnaire to measure the knowledge and experience of a patient managing chronic cancer pain on a scale from 0 (not at all) to 10

(extremely) (The City of Hope Pain & Palliative Care Resource Center, 2012). Patient who rated 0 to 2 would be categorized as no or acceptable pain, 3–5 categorized as mild pain, 6–8 moderate pain and 9–10 as severe pain. Patient pain questionnaire showed an acceptable internal consistency ( $\alpha = 0.73$ ).

### ***Fatigue***

The Chalder fatigue questionnaire is 11-item self-report questionnaire that assesses fatigue severity over the past 3 months on a 4-Likert scale (0 = better than usual to 3 = much worse than usual), with higher scores indicating greater fatigue (Cella & Chalder, 2010). In the present study, Chalder fatigue questionnaire showed a good internal consistency ( $\alpha = 0.88$ ).

### ***Illness acceptance***

Peace, equanimity and acceptance in the cancer experience (PEACE) scale is a 12-item questionnaire that used to assess the cancer patient's acceptance and their struggle regarding their illness on a 4-Likert scale (1 = 'not at all' to 4 = 'to a large extent') (Mack et al., 2008). This scale has two subscales: a 7-item Struggle with Illness and a 5-item Peaceful Acceptance. This scale showed good internal consistency with Cronbach's  $\alpha$  of 0.95 for Peaceful Acceptance subscale and Cronbach's  $\alpha$  of 0.8 for Struggle with Illness.

### ***Data analysis***

Data were analyzed by using the IBM SPSS statistics-version 22. Analysis of variance was also used to examine the effect of sleep quality, pain, fatigue and illness acceptance on psychological wellbeing. A p-value less than 0.05 was considered to be significant (Field, 2013).

## **RESULTS**

### **Cancer-related complaints**

#### ***Sleep quality***

Of 106 participants, 27.4% of the cancer patients reported to have poor sleep quality and 4.7% of them were having very poor sleep quality. Around 15% of the cancer patients spent half an hour to an hour to fall asleep, and 3% of them need more than an hour to sleep. Approximately 11.3% of them reported to have 5–6 h sleep per night and 3.8% reported to have less than 5 h sleep per night every day for the last month. There was no significant difference in reporting sleep quality regardless of types of cancer diagnosis and duration of having a cancer diagnosis. The newly diagnosed cancer patients reported to have poorer sleep quality than cancer patients who have a long history of cancer diagnosed,  $F(1, 104) = 4.00, p = 0.048$ .

#### ***Pain***

Of 106 cancer patients, 40.5% reported that if the pain was worsening, the condition of their cancer would get worse ( $n = 43$ ). A total of 50.8% of them reported that have severe pain and 27% reported to have moderate pain. Within this group, cancer patients believed that severe pain can be effectively relieved by having pain medicine (33.3%). Most of the patients believed that treatments other than medication, especially massage and heat can be effective.

There were significant differences in pain intensity between different cancer diagnosis,  $F(10, 95) = 2.36, p = 0.016$  but not with the duration of having a cancer diagnosis. Patients whose cancer cells have spread to three parts of their body (M: 7.75, SD: 1.5) was suffering a higher level of pain intensity than other cancer patients. This was followed by lung cancer patients (M: 7.33, SD: 3.06), thyroid cancer patient (M: 7.00, SD: 1.83), and have spread to two parts of the body (M: 6.17,

SD: 3.37). From the analysis, the newly diagnosed cancer patients have the most distressing due to their pain,  $F(1, 104) = 5.53$ ,  $p = 0.021$  and on their relations with family members,  $F(1, 104) = 8.23$ ,  $p = 0.005$ .

### ***Fatigue***

The cancer patients required in the present study reported a mean of fatigue of 15.9 (SD: 4.15). The descriptive analysis reported that 46.2% of them were having severe physical fatigue and 14.2% having moderate physical fatigue. There were 36.8% reported to have severe lower energy and 9.4% reported to have severe mental fatigue. There were significant differences between the type of cancer diagnosis in reporting the fatigue level,  $F(10, 95) = 2.24$ ,  $p = 0.021$ . Lung cancer patients (M: 21.67, SD: 3.06) significantly felt the fatigue more than other cancer patients. This was followed by thyroid cancer patient (M: 19.5, SD: 4.36), patients whose cancer cells have spread to three parts of their body (M: 18.76, SD: 2.87) and have spread to two parts of the body (M: 17.92, SD: 3.37).

### ***Illness acceptance***

Cancer patients reported a mean of 10.76 (SD: 4.69) for the struggle with illness and a mean of 16.41 (SD: 4.11) for peaceful acceptance. The intensity of struggling with illness remained similar in regardless of cancer diagnosis. There was a significant difference between cancer patients' peaceful acceptance of their illness with a different cancer diagnosis,  $F(10, 95) = 2.19$ ,  $p = 0.025$ . Rectal cancer patients (M: 19.5, SD: 0.71) have the highest level peaceful acceptance toward their disease, followed by ovarian cancer patients (M: 18.8, SD: 2.17), breast cancer (M: 17.35, SD: 3.40) and prostate cancer (M: 16.8, SD: 2.95). Lung cancer patient (M: 9.67, SD: 5.12) reported having the lowest level of peaceful acceptance. The ANOVA showed a significant difference in reporting the peaceful acceptance and duration of having a cancer diagnosis,  $F(19, 86) = 2.06$ ,  $p = 0.013$ . The result showed a significant positive linear relationship, indicating that the longer duration that cancer patients have, a better level of peaceful acceptance they would have ( $p = 0.014$ ). There was a significant gender difference in rating cancer patients' peaceful acceptance,  $F(1, 104) = 4.93$ ,  $p = 0.029$ , with females (M: 16.89, SD: 3.69) was easier to have peaceful acceptance than the male (M: 14.84, SD: 5.01).

### ***Psychological distresses***

The descriptive analysis reported a total mean of 4.87 (SD: 5.69) for depressive symptoms, a total mean of 4.64 (SD: 4.94) for anxiety symptoms and a total mean of 7.06 (SD: 6.70) for their stress level. The result showed that 17% ( $n = 18$ ) of the cancer patients exhibited severe depressive symptoms, 27.4% ( $n = 29$ ) exhibited severe anxiety symptoms and 28.3% ( $n = 30$ ) of severe level of stress. There was a significant difference in reporting depressive symptoms in regards to different cancer diagnosis,  $F(10, 95) = 2.76$ ,  $p = 0.005$ . Lung cancer patients (M: 10.33, SD: 8.96) exhibited the most depressive symptoms, followed by patients whose cancer cells have spread to two parts of their body (M= 9.58, SD = 4.96) and spread to three parts of their body (M: 8.00, SD: 6.27) as well as thyroid cancer (M: 8.00, SD: 6.98). A significant difference was found in reporting anxiety symptoms with different cancer diagnosis,  $F(10, 95) = 2.63$ ,  $p = 0.007$ . Lung cancer patients reported more anxiety symptoms than other cancer patients (M: 12.33, SD: 4.04). This was followed by thyroid cancer patients (M: 10.00, SD: 4.55), patients whose cancer cells have spread to two parts of their body (M: 7.25, SD: 5.34) and have spread to three parts of the body (M: 6.00, SD: 4.97). A significant difference was found in exhibiting stress levels in regards to different cancer diagnosis,  $F(10, 95) = 3.00$ ,  $p = 0.002$ . Thyroid cancer patients rated the highest level of stress (M: 13.75, SD: 3.50), followed by lung cancer (M: 13.0, SD: 5.20), patient whose



patients whose cancer cells have spread to two parts of their body (M: 12.58, SD: 5.47) and have spread to three parts of the body (M: 11.00, SD: 7.62). Cancer patients who were newly diagnosed exhibited more severe depressive symptoms ( $F(1, 104) = 7.99, p = 0.006$ ), anxiety symptoms ( $F(1, 104) = 18.87, p < 0.001$ ) and higher stress level ( $F(1, 104) = 11.17, p = 0.001$ ) as compared with those who have a long history of cancer diagnosis.

There was significant difference in illness acceptance for cancer patients with different sleep quality,  $F(3, 102) = 11.52, p < 0.001$ . Cancer patient with better sleep quality has better illness acceptance, this has shown a significant positive linear relationship ( $p < 0.001$ ). Pain intensity ( $F(3, 102) = 3.13, p = 0.029$ ) and fatigue level ( $F(16, 89) = 5.05, p < 0.001$ ) also significantly different with different levels of illness acceptance. The result showed a significant negative linear relationship, indicating cancer patients with less pain ( $p = 0.006$ ) and fatigue level ( $p < 0.001$ ) would have higher illness acceptance.

There were significant differences in reporting illness acceptance for cancer patients with different level of depressive symptoms ( $F(16, 89) = 9.99, p < 0.001$ ), anxiety symptoms ( $F(14, 91) = 6.87, p < 0.001$ ) and stress level ( $F(14, 91) = 7.55, p < 0.001$ ). All of these associations showed significant negative linear relationships ( $p < 0.001$ ). Cancer patients with a higher level of peaceful acceptance toward their illness, they were less likely to exhibit depressive symptoms, anxiety symptoms and higher stress level.

There were significant differences in reporting sleep quality for cancer patients with different level of depressive symptoms ( $F(3, 102) = 14.13, p < 0.001$ ), anxiety symptoms ( $F(3, 102) = 14.61, p < 0.001$ ) and the stress level ( $F(3, 102) = 11.32, p < 0.001$ ). The results showed a significant positive linear relationship between sleep qualities with psychological wellbeing. This indicated that the poorer sleep quality the cancer patients have, the more severe depressive, anxiety symptoms and higher stress level would be reported.

ANOVA result showed that pain intensity was significantly different for cancer patients with different level of depressive symptoms ( $F(3, 102) = 7.77, p < 0.001$ ), anxiety symptoms ( $F(3, 102) = 7.03, p < 0.001$ ) and stress level ( $F(3, 102) = 7.44, p < 0.001$ ). It showed a significant positive linear relationship, indicating the more severe the cancer patients felt the pain, the more severe depressive symptoms they would exhibit ( $p < 0.001$ ). Fatigue has a significant effect on depression symptoms among cancer patients,  $F(16, 89) = 7.40, p < 0.001$ . Fatigue also has significant effect on anxiety symptoms ( $F(16, 89) = 5.83, p < 0.001$ ) and stress level ( $F(16, 89) = 6.42, p < 0.001$ ). All of these three associations showed a significant positive linear relationship ( $p < 0.001$ ), indicating that cancer patients with more severe fatigue were more likely to have more severe depressive symptoms, anxiety symptoms and higher stress level.

## DISCUSSION

The prevalence rate of sleep quality, pain and fatigue were 27.4, 40.5 and 45%, respectively. Nearly one-fifth of the present participants reported to have longer sleep latency, less than 8 h sleep and were having problems in completing tasks during the daytime. This was consistent with other findings, for example, Zarogoulidis et al. (2013). The present prevalence of sleep quality and fatigue was lower than other findings (Berger et al., 2009; Biswal, Kumaraswamy, & Mukhtar, 2004; Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007; Savard & Savard, 2017). Cancer patients who were receiving treatment reported to be easier to feel fatigue and have poorer sleep quality as compared with those who had finished treatment (Tung et al., 2016). This may explain the lower prevalence found in the present study than other existing findings. Approximately 78%

of the present participants recruited have gone through their cancer treatment and were at regular follow-ups, thus, the rating of their sleep quality and fatigue were lower. A higher prevalence of pain was reported in the present study as compared with other studies (Czerw et al., 2017; G. C. Ng et al., 2017). Most of the cancer-related pain was remained untreated and most of the Malaysian cancer patients were still having a stigma in pain medication (Farooqui et al., 2011; Lim, 2008). There were only 24% of cancer patients who are suffering from cancer pain have received opioid analgesia in Malaysia (Lim, 2008).

The prevalence of psychological distresses was in line with other local findings (e.g., Hassan et al., 2015; C. G. Ng et al., 2017; G. C. Ng et al., 2017; Sharif, 2017). The prevalence of anxiety is higher than depression prevalence in the present study. This may due to the fear of cancer recurrence and uncertainty about the future as well as their treatment outcomes. This was in line to Ng *et al.* and Sharif findings among Malaysian cancer patients (Chong Guan Ng et al., 2017; Sharif, 2017). In terms of illness acceptance, rectal cancer patients in the present study followed by ovarian cancer patients and breast cancer patients were easier to accept their cancer than other cancer diagnoses whereas lung cancer patients reported to have the lowest level of illness acceptance. This was consistent with (Religioni, Czerw, & Deptala, 2015). More than a half of the women with breast cancer in Cipora *et al.* study considered themselves as fully valued and have no effect on their self-esteem which rated a higher level of illness acceptance (Cipora, Konieczny, & Sobieszczanski, 2018). From the present result, it may be presumed that the level of illness acceptance may be due to the cancer-related symptoms and psychological distresses suffered. Lung cancer patients followed by thyroid cancer patients reported poorer sleep quality, higher pain intensity and severe cancer-related fatigue than other types of cancer diagnosis. This was consistent with Chabowski *et al.* as they claimed that lung cancer patients showed higher scores of physical functioning and pain with low acceptance of illness (Chabowski et al., 2017). Our lung cancer patients reported having difficulties in their breathing in which affected their activity level during daytime and sleep at night. As compared with those who were newly diagnosed and diagnosed more than a year cancer patients, newly diagnosed cancer patients exhibited more severe cancer-related symptoms, and psychological distresses. Burgess et al. (2005) findings reported that the prevalence of depression and anxiety dropped from 48% (first year of diagnosis) to 15% (the fifth year of diagnosis). Cancer patients experienced the fluctuating course of psychological distress throughout the diagnosis, treatment phases and follow-up phase (C. G. Ng, 2010; So et al., 2014). The levels of anxiety reduced significantly at 6 and 12 months if a proper intervention was given [40]. Thus, early detection and intervention of psychological problems among cancer patients would be important to reduce the complication of a treatment plan and possible reluctance behaviors among cancer patients (Hassan et al., 2015).

From the model which conceptualized the impact of cancer-related symptoms on psychological distresses indicated that relieving cancer-related symptoms are an important strategy to improve or prevent psychological distresses. Most of the studies focused on investigating the effectiveness of adjunct psychotherapy conducted during prehabilitation; however, the mechanisms underlying these psychotherapies are important. Patients' illness acceptance served as a buffering factor as increasing their acceptance of illness would decrease the effect of cancer-related complaints on patients' psychological distresses. Although from the common sense point of view, cancer patients who reported to have more treatment-related impacts, including poor sleeping quality, higher levels of pain and fatigue would have higher level of psychological distresses. It implied that cancer patient's readiness to accept their diagnosis and vulnerability, as well as to change their lifestyles should be considered as part of the cancer treatment plan. Several studies also showed some benefits

of other psychological interventions such as motivational interviewing (MI) that tapped with the transtheoretical model in managing patients with cancer and increasing treatment adherence (B. P. Chen et al., 2017; Thomas, Fahey, & Christine Miaskowski, 2012). However, limited RCTs with the focus in MI and precancer treatment (prehabilitation) were conducted or were unclear with the time of enrolment. The combination of MI with psychological intervention in exploring and resolving ambivalence about behavioral change need further investigation, especially in cancer prehabilitation study.

Malaysian cancer patients who delayed in seeking treatment were mainly due to the fear of cancer-related symptoms (Farooqui et al., 2011). Malaysian cancer patients would perceive a cancer treatment as effective when they were exposed to the scientific method of preparation (Farooqui et al., 2011). Thus, an adjunct psychological-based prehabilitation for the cancer patients who were in the waiting list for cancer treatment is needed. This adjunct psychological-based prehabilitation would need to target the possible treatment side effect, thus prepared the patients in more effectively cope with their struggle when they received cancer treatment. Hence, this study was important to provide information about Malaysian cancer patients' needs in preparation for cancer treatments.

### **Limitations & strengths**

Limitations of the current study include moderate size and rather a heterogeneous character of the study group. This included patients with different cancer diagnosis and various stages of cancer as it was still in the exploratory stage. In the future study, stages of cancer would be one of the important variables to be included. The study was mostly based on self-report questionnaires that illustrate the subjective experiences of cancer-related symptoms and psychological distresses. Despite limitations, the current study provides evidence for the association between cancer-related symptoms, illness acceptance and psychological distresses. To the best of our knowledge, the association between these three in cancer patients has not been studied. Understanding the role of acceptance of illness may help to develop intervention programs and improve psycho-oncology management.

### **Future research**

After reviewing the cancer management that suggested to be implemented in Malaysia (Lim, 2008; Ministry of Health Malaysia, 2017), they acknowledged the need for psychosocial care. However, due to lack of manpower and lack of adequate education, awareness of psychological distresses and its impact was still having room for improvement. This was consistent with the finding conducted across ten countries to elucidate the perspective of both physicians and patients (A. W. Group et al., 2015). More than half of the physicians commented that they were lacking adequate education for cancer management. The present result suggested a change in management practices, for example, implemented an adjunct psychological-based prehabilitation may be required on the part of physicians and patients in cancer management. Thus, a systematic study should be conducted in the future to examine the feasibility of the adjunct prehabilitation for cancer treatment preparation. Newly diagnosed cancer patients with longer waiting time were more likely to result in worse prognosis (Biagi et al., 2011; Z. Chen, King, Pearcey, Kerba, & Mackillop, 2008). Both the systematic review and meta-analysis, a longer waiting time for radiotherapy was significantly associated with a lower rate of both the overall survival and disease-free survival among the cancer patients (Biagi et al., 2011; Z. Chen et al., 2008). Psychological-based prehabilitation during the waiting time is necessary to provide support and enhance patients' coping skills for current and future impairment in which may promote better health outcomes. Cancer patients



described that the transition from health to illness and the period of waiting time for treatment extremely struggled. They were in the state of loneliness and were placed in a vulnerable position (Ekwall, Ternstedt, & Sorbe, 2007; Lehto, 2011). In the future, Phase II and III of the present study may consider psychological intervention that focused on illness acceptance and early training of coping strategies makes good use of the waiting time for the patients to acclimate the transition period and ready for future challenges followed with better treatment adherence in which would minimize the effect of delayed cancer treatment and directly promote a better outcome (Z. Chen et al., 2008; Silver & Baima, 2013).

## CONCLUSION

This study had revealed a significant association of cancer-related symptoms, illness acceptance and psychological distresses commonly experienced by local cancer patients. The high prevalence of cancer-related symptoms and its impact on psychological distresses were reported in the present study. There were significant differences in reporting their psychological issues and cancer-related complaints with regards to different cancer diagnosis. An intervention study that focused on psychological based pre- and posthabilitation that served illness acceptance as one of the targets would be needed for the local cancer patient.

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**Table 1. Descriptive characteristics of cancer patients (N = 106).**

Characteristic	Total sample
Age (M, SD)	61.6 (11.69)
Gender (n, %):	
– Female	81 (76.4)
– Male	25 (23.6)
Ethnicity (%):	
– Malay	50.9
– Chinese	40.6
– Indian	6.6
– Others	1.9
Type of cancer (n, %):	12.3
– Breast	51 (48.1)
– Colon	10 (9.4)
– Prostate	5 (4.7)
– Lung	3 (2.8)
– Neck/thyroid	4 (3.8)
– Rectal	2 (1.9)
– Kidney	3 (2.8)
– Ovary	5 (4.7)
– Others (i.e., lymph cancer, brain cancer, bone cancer and skin cancer)	7 (6.6)
– Spread to two cancers	12 (11.3)
– Spread to three cancers	4 (3.8)
Duration <sup>†</sup> (M, SD)	4.90 (4.39)

<sup>†</sup>Duration of diagnosed with cancer: date when the present participant was administered (year) – date when the participant received the cancer diagnosis (year).  
M: Mean; SD: Standard deviation.



# Surrender to God and Parenting Stress among Mothers with Autistic Children

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## Abstract

*Purpose:* This study is a survey study that examines the role of surrender to god towards parenting stress among mothers with autistic children.

*Methodology:* This study involved 40 mothers with autistic children start from early childhood age until elementary school age as respondents. The respondents obtained from a purposive sampling technique in several special schools at Banjarmasin with the age ranged from 23 - 50 Years. The measuring instrument used in this study is Surrender to God Scale by Wong-McDonald and Gorschuh (2000) and Parenting Stress Index (PSI) developed by Abidin (Ahern, 2004). Data analysis in this study was conducted by Spearman's rho correlation.

*Results:* This study showed that there is no significant correlation between surrender to god and parenting stress among mothers with autistic children. The result will be discussed further in this article.

## INTRODUCTION

Parental stress is often experienced by every parent. Abidin (Ahern, 2004) states that parenting stress is excessive anxiety and tension, especially related to its role as a parent and the interaction between parent and child. Another definition was disclosed by Cooper, McLanahan, Meadows, and Brooke-Guns (2009) which states that parenting stress is a condition or feeling of parents when they feel unable to fill the demands of parental roles because of insufficient personal and social resources. This causes psychological pressure felt by parents, in this case especially the mother. The stages of child development and diverse characteristics of children often become risk factors. However, this stress condition is more increased if the parents have children with special needs.

This phenomenon is demonstrated by previous research conducted by Lopez, Clifford, Minnes, and Oulette-Kuntz (2008). The study compared between the parents of children with special needs and those who did not. The study was conducted on 46 parents through the interview method. The result is stress levels of parents who have children with special needs turned out to be higher compared to the parents who have children with normal developmental stages. Other research was conducted by Yousefia, Far, and Abdolahian (2011). The research team examined the comparison of stress conditions among parents of children with ADHD and those who did not. The result is that there are significant differences between the two in terms of parenting style and stress level. Parents who have children with special needs have been shown to have higher levels of stress. This facts strengthen the existence of crucial problems among parents who have children with special needs.

In fact, the last few decades showed the fact that there is an increasing prevalence of children with autism in Indonesia. This is indicated by the following news excerpts showing an increasing number of people with autism from year to year. As reported from [www.jpnn.com](http://www.jpnn.com) site, that indeed there is no definitive data about the number of children with autism in Indonesia. However, the data owned by UNESCO in 2011 declare, there is about 35 million people with autism exist in the world. That means on the average of 6 out of 1000 people in the world have autism. Likewise

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with the study of the Center for Disease Control (CDC) of the United States in 2008, stated that the ratio of autism in 8-years-old children diagnosed with autism was 1: 80. This is based on global estimates, so that giving rise to vigilance due to the increasing number of people with autism in Indonesia.

The characteristics of autism, raises its own challenges for parents in dealing with it. Some of the characteristics of an autistic child according to Kanner (in Wenar & Kerig, 2006) are socially isolated behavior, a preference for the same/ repetitive, and use of non-communicative language. In addition, based on the study conducted by Bashir, Bashir, Lone, and Ahmad (2014) there are several behaviors of autistic children which tend to be a trigger for parenting stress. Some of these behaviors such as overcoming child behavior problems, teaching children to communicate and be able to develop themselves, keep the children from danger, and prepare the children for adulthood. Various issues are susceptible to cause stress for parents. Abidin (in Ahern, 2004) explains that stress will direct the family toward parental dysfunction. This has implications for the inability of parents to provide responses that are appropriate to the child's needs. Certainly, if this problem being ignored, it will make the relationship between parent and child full of tension and frustration. Abidin (in Ahern, 2004) also explains that there are three aspects that can influence parenting stress, that is parenting stress, children difficulties, and dysfunctional interactions between parent and child.

Related to that case, the mother still has a crucial role in the development of a child. In various cultural contexts, especially in Indonesia, mother still have a role as the primary caregiver in the family. Similarly with the scope of children's development with special needs, especially children with autism. The character of the disorder that is owned by the child has different characteristics from other special needs. For example, children's limitations in communicate actively, low socialization abilities, and tend to be difficult to develop attachment to others (Wenar & Kerig, 2006). This statement is supported by a meta-analysis research from Hayes and Watson (2013) which stated that parents with autistic children have high level of stress, especially related to the problematic behavior in children. This is certainly tests the parenting skills owned by the mother. Therefore, parenting stress when raising children was higher felt by mothers compared to fathers when taking care a children with autism.

In fact, parenting stress has a negative impact on a woman's physical health and mental well-being. Some of these impacts such as the emergence of problems in marital quality and psychological well-being (Lavee, Sharlin, & Katz, 1996). If the mother experiences high parental stress then the quality of marriage with a partner will tend to decrease. Conflicts with partners are usually prone to be arise in stressful situations. This problem will lead to the parenting given by parents. In addition, the impact of parenting stress also appears on the child's development. Research from Anthony et al. (2005) shows that parental stress will affect children's social competence in school and problematic behavior (internalization and externalization). The example of internalized behavioral problem is withdrawal behavior in children, and barriers to expressing emotions adequately. Whereas, the examples of externalized behavioral problem are aggressiveness with peers and other social skills barriers. This is supported by the research conducted by Anthony et al. (2005) that children's social competencies tend to be low when the parenting stress is high. Likewise, the tendency for problematic behavior, start from the child becomes aggressive or even withdraws. The effects of parenting stress indicates the existence of variations.

There are several factors that are thought to take effect on parenting stress. One of factors that plays an important role is the ability to coping with stress among the mother. In general there are two types of coping, that is coping that focuses on cognitive and emotional (Lazarus & Folkman, 1984). However, in its development, there are additional types of coping, such as religious coping

(Pargament, Koenig, & Perez, 2000). The definition of religious coping is a form of coping based on the important functions of religiosity such as the search for meaning, control, comfort/spirituality, intimacy, and life transformation (Pargament, Koenig, & Perez, 2000). Clements and Ermakova (2012) found that the level of religiosity was negatively correlated with the level of stress experienced by individuals. Another finding is that stress reduction comes from the concept of surrender to god which is a part of religiosity.

According to Nelson (2009), surrender to god is a form of active submission to god that is characterized by a high understanding of locus of control that comes from god. This form of surrender is supported by the belief that God will help individual's coping through the meaning and the purpose of god for all events in life. Another definition is stated by Wong-McDonald and Gorsuch (2000). Both experts interpret surrender to god as a form of personal activity to obey the rules of god, and not just being passive by waiting for god to arrange everything. This is in line with the definition revealed by Nelson (2009). Based on these two definitions, it can be concluded that surrender to god is a form of coping that emphasizes the activeness of individuals to remain obedient to god's provisions as well as an understanding of the purpose and the meaning in everything happened in individual life.

In the case of parenting stress with special needs children, including autism, shows that there is an influence of religious coping on parenting stress. Some aspects of religious coping according to Pargament, Feuille, and Burdzy (2011), that is: 1) Collaborative religious coping that is seeking control over the problems of life by asking for help from god. 2) Active religious surrender that is actively giving control to god over the problems in his life. 3) Passive religious deferral is an individual passively waiting for god's help to control the problems that occur in his life. 4) Pleading for direct intercession that is looking for control over stressors or problems in life through requests/prayers for themselves or others. 5) Self-directed religious coping is seeking control over the problems faced through personal initiative and not referring to god.

The first study was conducted by Durban et.al. (2012) on parents with children who experienced developmental delays. The result showed that there are several coping programs developed by parents to deal with the parenting stress. Religious coping is fourth. Parents re-meaning the events that occur in their lives. Rituals that exist in religion also help the parents deal with stress that occurs while taking care for children. Afterward, Clements and Ermakova (2012) also found that the level of religiosity was negatively correlated with the level of stress experienced by individuals. The explanation of the research is that the belief in a person in God, especially in everything that happens in his life will help them release the pressure in their lives. Individuals can be less stressed because they feel that there is more power that will help them through all problems. This affects the perception of the stresses that occur in life. From this explanation it appears that there is a transformation of the meaning of life.

Therefore, religious coping is thought to have an influence on individual stress conditions. Based on the explanation above, the construct of surrender to God is thought to have an influence on the parenting stress among mothers with autistic children.

## **METHOD**

### **Participant**

The participant in this study are 40 mothers with autistic children from three diverse special schools in Banjarmasin, South Kalimantan. The age ranged from 23 – 50 years. According to the table 1 and table 2, most of them are 30-36 years, and work as housewives.

**Table 1.** Age range of participant

Range Age	Numbers	Frequency
23 – 29	12	29.5%
30 – 36	14	34.4%
37 – 43	11	27.9%
44 – 50	3	8.2%

**Table 2.** Participant's Working Type

Working Types	Numbers	Frequency
Housewife	24	60.7%
General employees	5	13.1%
Government employees	4	9.8%
Others	7	16.4%

## Measures

### *Surrender to God Scale*

This measuring instrument developed by Wong-McDonald and Gorschuh (2000) which refers to the Religious Problem Solving Scale of the Pargament. The instrument is an unidimensional scale consisting of 12 statement items that all of the items are favorable, with five response options. The system for scoring start from 1 up to 5. The total score of this whole item will describe the level of surrender to God. The testing of measuring instrument showed that the Cronbach Alpha value was 0.805, with a corrected item total correlation score ranging from 0.196-0.740. This result shows a high level of reliability based on the scores obtained.

### *Parenting Stress Index (PSI)*

This measuring instrument has 36 items developed by Abidin (Ahern, 2004). The aspects measured in this instrument are parental stress situation, dysfunctional of interaction between parent and child, and children difficulties. The whole items in this measuring instrument are favorable. This measuring instrument has 5 response options with scores range from 1 up to 5. The total score of the whole item will be an indicator of the high and low stress of parenting in the mother. At the first, this measuring instrument had 36 favorable question items. After testing the validity through face validity with the supervisor, it was agreed that there were 13 items that were deleted because of the corrected item total correlation score showed  $<0.3$ , so that it was declared invalid for this study. Thus, the total number of question items used was only 23 items. Furthermore, this measuring instrument showed that the Cronbach Alpha value was 0.937.

## RESULT

### Normality Test

As the data shown in table 4, it was found that the data distribution of parenting stress variable is not normally distributed ( $p < 0.05$ ), while the data distribution of surrender of god variable has been normally distributed ( $p > 0.05$ ).



**Table 3.** The result of Normality test.

Variables	KS-Z	p
Parenting stress	0.141	0.044
Surrender to god	0.129	0.090

### Linearity Test

The results of linearity test indicated the value of  $F = 0.702$  with  $p = 0.41$ . The results of the analysis showed that the relationship between surrender of god and parenting stress is not linear.

### Hypothesis Test

The results of the normality and linearity tests do not fill the requirements to be able to do hypothesis testing using parametric methods. Therefore, this study uses non-parametric hypothesis testing with Spearman-Rho correlations. According to the table 5, the results of the hypothesis test showed the value of  $r = 0.153$  with  $p = 0.173$  ( $p > 0.05$ ). Thus, it can be concluded that there is no significant correlation between surrender to God and the level of parenting stress among mothers with autistic children.

**Table 4.** The result of Hypothesis test with Spearman's rho correlation

Variables	r	p	r <sup>2</sup>
Surrender to god and parenting stress	0.153	0.173	0.023

## DISCUSSION

The results of this study showed that there is no significant correlation between surrender to god and parenting stress among mothers with autistic children. This result gives its own meaning. In terms of effective contributions, it also does not show a significant amount with only 2.34%. These findings require further understanding in order to be interpreted.

Referring to the results of meta-analysis research from Mancil, Boyd, and Bedesem (2009) showed that among the various types of special needs, the highest level of parental stress is found in parents with autistic children. This fact showed the more complex parenting challenges compared with any other special needs. Furthermore, still referring to Mancil, Boyd, and Bedesem (2009), coping strategies on parenting stress with autistic children have varied patterns. On the one hand, there is a role from the external side, for example social support, and there is a role from the internal side as well. These factors interact continuously and simultaneously. Therefore, it is quite difficult to determine the single factor of parenting stress with autistic children.

From the research above shows that there are relatively unique patterns and different in parenting with autistic children. The condition of a child who does need extra attention also has different implications. From the explanation above, it appears that several variables play a role simultaneously in affecting the parenting stress with autistic children. The results of the research above indicate that it becomes one of the weaknesses of the study if it only examines an independent variable by itself. Another study examining the relationship between the two variables was conducted by Faciane (2015) who examined the effects of religiosity and anxiety on parents with autistic children. The results of this study revealed that the link between the two matters did not take place directly. There are influential mediator variables in it. Faciane (2015) explains that if there is support from a partner, then the mother will have a more positive

coping ability. Furthermore, the positive coping developed tends to bring the mother closer to her religious side, which is closeness to god. Based on this closeness, the mother's perception of her child becomes more positive.

Subsequently, research from Hastings et al. (2005) showed there are variations in the correlation of some coping forms with stress among mothers who have autistic children. The result showed that there is a significant positive correlation between active avoidance and stress. However, the insignificant correlation was seen in the link between problem focused coping, positive coping, and religious coping. Moreover, the correlation coefficient of religious coping is classified as the lowest among other types. Arguments from Hastings et al. (2005) explained that the possibility when the mothers applied religious coping, it will be mixing with the element of denial. This is possible if the coping is done in order to avoid reality. Therefore, the results of the study mentioned above are in line with the analysis of this study.

Another study conducted by Davis (2016) is also in line with the results of this study. That study involved 41 mothers with autistic children. The variables measured were religious coping with parenting stress and maternal psychological well-being. The result showed that there is no significant correlation between religious coping and psychological well-being. Further analysis has been carried out by using religious coping as a moderator variable, and the result showed same like before that there is no significant correlation with parenting stress or psychological well-being. From the discussion of this research, the researchers considering to see the subject's attachment to rituals and involvement in religious activities as one of the influential factors for further studies.

Through the explanation above, the insignificant correlation in this study becomes easier to understand. The concept of religious coping based on several studies cannot stand alone to overcome parenting stress among mothers with autism children. After reviewing some literature references, researchers found that social support, both through informational support, instrumental support, and other forms of support becomes more concrete in overcome the mother's parenting stress. Religious coping, including surrender to god, will give an impact when correlated with other variables.

This result is interesting to examine further. Some people tend to perceive the concept of surrender to God as a form of total surrender by minimizing effort. Even though, referring to Wong-McDonald and Gorsuch (2000) showed that surrender to god is a form of personal activity to obey god's rules, and not merely to behave passively by waiting for God to arrange everything. This is also supported by research from Grossoehme et al. (2013) that belief in God actually has a positive impact as demonstrated by parents' efforts to bring their children to the medical treatment routinely.

This research has several research weaknesses. The first weakness is the condition/level of autism of children who may vary. Researchers found it difficult to classify the level of autism disorders in children, because some mothers who fill the questionnaire do not understand the level of the children disorders, whether it is in the category of mild, moderate, or severe. Then, the second weakness is related to the diverse age of the children. This is might affect the results of the study, because the parenting challenges in each stage of age may be different. Furthermore, limitations were found in the limited subjects. Maternal involvement data in religious activities also have not been studied further. Even though, the data might be important to complete the discussion and become additional variables containing important information.

## CONCLUSION

This study showed that there is no significant correlation between surrender to god and parenting stress among mothers with autistic children. However, the descriptive analysis showed the differences in responses between mothers with high and low parenting stress.

## ACKNOWLEDGEMENTS

We thank all of the principals, teachers, and parents of students at the participating schools in Banjarmasin, South Kalimantan.

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