ORIGINAL ARTICLE

Depression and Coping Strategies among Parents of Children with Cancer in Malaysia

YEAP SL¹, MAHADEVAN R², YUSOF YB¹, ALIAS H³, ABD RAHMAN FN²

¹Department of Psychiatry, Penang General Hospital, Jalan Residensi, Georgetown, Penang, Malaysia

²Department of Psychiatry, ³Department of Paediatrics, Faculty of Medicine, Universiti Kebangsaan Malaysia, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Cheras, Kuala Lumpur, Malaysia

Received: 13 Dec 2023 / Accepted: 11 Mar 2024

ABSTRAK

Gejala kemurungan telah dilaporkan lebih ketara di kalangan ibu bapa yang mempunyai anak yang menghidap kanser. Kajian ini bertujuan untuk menentukan prevalens gangguan kemurungan utama (MDD) dan kaitannya dengan faktor sosio-demografi dan strategi daya tindak dalam kalangan ibu bapa kanak-kanak yang menghidapkanser di Pusat Perubatan Universiti Kebangsaan Malaysia (UKMMC) dan Hospital Besar Pulau Pinang (PGH). Dalam kajian keratan rentas, peserta telah disaring untuk kemurungan dengan menggunakan Soal Selidik Kesihatan Pesakit (PHQ-9). Diagnosis MDD bagi mereka yang berisiko tinggi telah disahkan menggunakan Mini International Neuropsychiatric Interview (M.I.N.I.). Strategi daya tindak dinilai menggunakan skala 'Coping Orientation to Problems Experienced Inventory' (Brief COPE). Daripada jumlah 162 ibu bapa dalam kajian ini, 17.3% peserta mempunyai simptom kemurungan sederhana hingga teruk. Kira-kira 10% mempunyai simptom sederhana manakala 7.4% mempunyai simptom yang teruk. Kesemua 7.4% telah didiagnosis dengan MDD. Peserta yang menggunakan penafian (ß = 0.611), pelepasan tingkah laku (β = 0.992) dan menyalahkan diri sendiri (β = 0.682) mempunyai kemungkinan lebih tinggi untuk mengalami gejala kemurungan. Tempoh penyakit anak (ß = -0.028) mempunyai kesan negatif yang ketara ke atas skor PHQ-9. Kesimpulannya, ibu bapayang mempunyai anak yang menghidap kanser harus disaring untuk kemurungan pada masa yang mencabar ini.

Kata kunci: Ibu bapa; kanser; kemurungan

Address for correspondence and reprint requests: Associate Professor Dr. Fairuz Nazri Abd Rahman. Child and Adolescent Psychiatry Unit, Department of Psychiatry, Faculty of Medicine, Universiti Kebangsaan Malaysia, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Cheras, Kuala Lumpur, Malaysia. Tel: +6019 2710792 Email: fairuzn@ppukm.ukm.edu.my

ABSTRACT

Depressive symptoms have been reported to be more prominent in parents of children with cancer. This study aimed to determine the prevalence of major depressive disorder (MDD) and its association with socio-demographic factors and coping strategies among parents of children with cancer at Universiti Kebangsaan Malaysia Medical Centre (UKMMC) and Penang General Hospital (PGH). In a cross-sectional study, participants were screened for depression using the Patient Health Questionnaire (PHQ-9). The diagnosis of MDD for those with high risk was established using the Mini International Neuropsychiatric Interview (M.I.N.I.). Coping strategies were assessed using Coping Orientation to Problems Experienced Inventory (Brief COPE) scale. Out of the 162 parents included in the study, 17.3% of participants had moderate to severe depressive symptoms. About 10% had moderate symptoms while 7.4% had severe symptoms. All 7.4% were diagnosed with MDD. Participants who adopted the use of denial (ß = 0.611), behavioural disengagement (β = 0.992) and self blame (β = 0.682) had higher likelihood of having depressive symptoms. Child's duration of illness (ß = -0.028) had a significant negative impact on PHQ-9 scores. In conclusion, parents of children with cancer should be screened for depression during this challenging time.

Keywords: Cancer; depression; parent

INTRODUCTION

Childhood cancer is considered as a life-threatening disease that affects the social, mental, physical and even economical status of both the child and the parents/caregiver (Alavian et al. 2015). The global statistics of children aged 0-19 years with cancer is expected to increase by 429,000 annually (Lam et al. 2019). Between 2007 to 2011, Malaysia recorded a total of 3829 cases of childhood cancer aged 0 to 18, with the 3 commonest cancers being leukemia, brain/nervous system tumors and lymphoma (Azizah et al. 2016). Although childhood cancer cases appear to be relatively few as compared to cancer in other age groups, it carries huge implications to the children and their family members. The diagnosis of cancer itself is sufficient to bring intense fear and despair to them (Cernvall et al. 2013). Parents have reported that their interfamily and social relationships had been significantly affected after the diagnosis was made on their children (Elcigil & Conk 2010). Many social activities had to be given up (Elcigil & Conk 2010). Employment disruptions, financial burden, spiritual issues and other psychosocial problems were frequently associated with the situation (Kostak & Avci 2013: Warner et al. 2015). The challenges faced by caregivers were not limited to financial, but also involved medical caregiving for their ill child; emotional caregiving for their ill child; and caregiving for the siblings of the ill child (Rajaratnam 2013). Caring for patients with poor functional status were more likely to place caregivers in a considerable poor psychological health outcome of depression (Ghazali 2021). The stress experienced by these parents could last an extended period of time (Norberg & Boman 2008).

Considering the significant amount of stress on parents of children with cancer, it is hypothesised that these parents are more vulnerable to depression. Parents with cancer wards had been found to experience a significant level of psychological distress (Boman et al. 2003; Grootenhuis & Last 1997; Rosenberg et al. 2013). In a study of 336 parents of children with cancer aged 0 to 16 years, the rate of depression among these parents, using the Centre for Epidemiologic Studies Depression Scale, have been reported to be as high as 70% when compared to parents with healthy children (Al-Maliki et al. 2016; Ghufran et al. 2014; Norberg & Boman 2008). Statistics from previous research also indicate that parents caring for children with cancer were five times more likely to report depressive symptoms (Creswell et al. 2014). This could interfere with their ability to care for themselves, the child with cancer, as well as other children at home.

Coping strategies refer to ways people behave in response to stress or undesirable occurrences (Carver et al. 1989). The ability of the parents to care for the child with cancer has been shown to be affected by how they cope with the diagnosis and consequences (James et al. 2002). Balancing care for the child, family and one's social life requires high levels of coping. However, because humans differ, coping strategies also differ from one another. Parents with better coping skills were found to have a lower level of anxiety and depression (Norberg et al. 2005). Moreover, as a caregiver, good coping mechanisms can be difficult to attain due to fear of uncertainty and emotional attachment to the child (Tang et al. 2021).

Ultimately, the inability to adopt a suitable coping mechanism can significantly affect the child's health outcome and survival (Emerson & Bögels 2017). For instance, a lower level of anxiety and depression was associated with a more frequent use of active problem-focusing and a less frequent use of avoidance behavior (Norberg et al. 2005). It is important to understand the coping strategies utilised by these parents so that healthy behaviours in reducing risk of depression can be encouraged and vice versa.

Many of the studies done were carried out in Western countries and they mostly focused on parental stress/distress level, depressive and anxiety symptoms rather than a clear diagnosis of depressive disorder among these parents. In Malaysia, data regarding depression and coping strategies among parents of children with cancer are still limited despite research highlighting that these parents are at a higher risk. Aside from screening for depressive symptoms,

this study also intended to determine the rate of MDD and its association with various coping strategies among parents of children with cancer in a clinical setting. Parents who required attention were hence referred to the psychiatric clinic for early intervention.

MATERIALS AND METHODS

A cross-sectional study was conducted on parents of children with cancer who attended the pediatric oncology wards and clinics in two centers which the researchers had access to, which were in the Universiti Kebangsaan Malaysia Medical Centre (UKMMC) and Penang General Hospital (PGH), from September 2016 to November 2017. Ethical clearance was obtained from the Medical Ethics Research Committee. UKM (FF-2016-406) and the Ministry of Health Medical Research Ethic Committee.

The study adopted a convenient sampling approach. A total of 162 parents who could understand either English or Malay language and who had consented to participate in the study were recruited for the study. The questionnaires included both English and Malay language and participants provided responses in the language they were more convenient with.

Study Sample

The 2020 Malaysian pediatric population is estimated as approximately 7.62 million (DOSM, 2020). Unfortunately, the rate of childhood cancer has not been academically addressed in Malaysia.

This can be associated with its rarity (Patel et. al. 2020). Nonetheless, the World Health Organisation estimated that 400,000 children are victims of cancer globally equivalent to 0.02% (WHO 2021) of the world pediatric population (0-19 years). In addition, the prevalence of depression in Malaysia ranged from 8 to 12% (Ng 2014). Hence, these rateswere adopted in the study to estimate the required sample size. Hence, we estimated a minimum of 162 parents of children with cancer were required to examine the factors influencing depression level among this group in Malaysia.

Data Collection

Convenience sampling was used. An information sheet was provided and informed consent was obtained from all the participants. Participants' sociodemographic data were obtained using a self-administered questionnaire. Data collected including parental age, sex, ethnicity, religion, marital status, number of children, primary carer of the child, education level, employment status, monthly household income and presence of shared caregiving.

Data regarding the sick child was also collected which consisted of the child's age, sex, age at diagnosis of cancer, time since diagnosis, type of cancer and current treatment status. Information was obtained from the child's medical notes if the parents were unsure about certain items.

The Patient Health Questionnaire (PHQ-9) was used to determine depressive symptoms amongst parents of children with cancer. Both English

and Malay versions of PHQ-9 were used to detect participants who were at risk for depression. It was a self-report questionnaire used to detect depressive symptoms based on the Diagnostic and Statistical Manual of Mental Disorders – fourth edition (DSM-IV) criteria.

The Brief COPE Inventory was used to collect information on which coping strategies these parents had mostly adopted. For the clinical assessment, the Mini International Neuropsychiatric Interview (M.I.N.I) was used to further assess parents who scored 10 or more in the PHQ-9.

Patient Health Questionnaire (PHQ-9)

A simplified version of PRIME-MD (Primary Care Evaluation of Mental Disorder) called the PHQ was developed (Spitzer et al. 1999). Since then researchers have continued to improve the validity of the PHQ. The PHQ-9 is the most commonly used instrument for assessing mental health status both in a clinical and research setting. It consists of a total of 9 items, each with scores from 0 to 3. Total scores ranged from 0 to 27. A cut-off point of 10 or more was used to identify those who were at risk and who would be further assessed with M.I.N.I. This cut-off point has been shown to have a sensitivity of 88% and a specificity of 88% for major depression (Kroenke et al. 2001). The Malay version of PHQ-9 had been validated with a reported sensitivity of 87% and a specificity of 82% (Sherina et al. 2012). PHQ-9 scores of 5 to 10 and above 10 were classified as mild to moderate depression and moderately severe to severe depression respectively.

Brief COPE Inventory

Coping strategies of participants were assessed using the Coping Orientation to Problems Experienced Inventory (Brief COPE) Inventory (Carver 1997). It is a shorter version of the original COPE inventory and consists of 28 items to assess 14 coping types, namely self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame. Respondents rated each item on a 4-point Likert scale. The scores for each coping mechanism ranged from 0 to 8. With 0 implying the non-use of such coping strategies and 8 implying total dependent (use) of the coping strategies. The Brief COPE Inventory has been validated in various settings and has been cited by many articles. A Malay version is available and has been validated (Yusoff et al. 2009).

Mini International Neuropsychiatric Interview (M.I.N.I.)

The PHQ-9 was used as a screening instrument to detect levels of depressive disorder among parents of children with cancer. Although parents with a score more than 10 were indicated to have a major depressive disorder, further assessment was made using the M.I.N.I instrument. The PHQ-9 is a valid instrument to measure MDD in a

clinical setting (Levis et al. 2019; Sun et al. 2020), nonetheless the PHQ-9 has a less specificity relative to the M.I.N.I. The M.I.N.I is a clinician-administered structured interview for the diagnosis of major psychiatric disorders in DSM-IV and International Classification of Diseases – Tenth edition (ICD-10), It has been validated against the Structured Clinical Interview for DSM-III-R (SCID) the Composite and International Diagnostic Interview (CIDI), and has been shown to have high validity and reliability (Sheehan et al. 1998). It can also be administered in a short period of time. Translated versions are not required in this study as the M.I.N.I. is clinician rated, and the clinician was trained in English. In this study, only Module A for the diagnosis of Major Depressive Disorder was used.

Statistical Analysis

All analyses were performed using the Statistical Package for Social Sciences (SPSS) Version 27 licensed to UKM. The PHQ-9 is an ordinal scale ranging from 0 to 27. Other variables in the study comprised nominal, metric and ordinal scales. In cases where the independent variable was categorical (ordinal or nominal), analysis of variance was used to test the difference in means among the categories. When the independent variable was continuous, then a Spearman rank correlation was used to find any significant correlation with the PHQ9 scores. In addition, that showed significant variables p-value with the PHQ9 score were recruited in the predictive analysis. A regression analysis was performed

to obtain predictors of depression. A p-value of less than 0.05 was considered statistically significant at 95% confidence interval.

RESULTS

There were 5 parents who refused to participate out of the 167 parents who were approached for participation. Therefore, a total of 162 participants were recruited. The mean age of the 162 participants in the study was 37.5 vears of which the majorities (84%) were female (Table 1). Males had higher mean PHQ-9 scores compared to females. More than three quarters were Malay and they had the lowest PHQ-9 scores. Majority (76.5%) were Muslims. They also had the lowest PHQ-9 scores relative to other religious participants faiths. The married constituted 95% of the study sample. Although the married category had the least PHQ 9 scores, this assumption might be biased due to other categories (separated, widowed and not married) being not well represented in the study. For every 10 participants, 7 had between 1 to 3 children. As the number of children increased, the mean PHQ-9 score decreased. However, this relationship was not significant at the 5% confidence interval. With respect to education, 31.5% and 61.7% had at least tertiary and secondary education respectively. We found that the higher the education, the lower the mean PHQ-9 score, which was statistically significant. Just as in the case of marital status, the categories in the educational level were not well represented in the study, hence, there is need for

TABLE 1: Parental demographics, support for parents and mean PHQ-9 scores

Variable	N (%)	Mean (SD)	Mean PHQ 9	(Corr.) p-value
Age		37.52 (7.044)		(-0.166) 0.035**
Gender				0.397
Male	26 (16.0)		6.73	
Female	136 (84.0)		5.80	
Race				0.307
Malay	123 (75.9)		5.63	
Chinese	22 (13.6)		6.18	
Indian	14 (8.6)		8.36	
Others	3 (1.9)		6.00	
Religion				0.282
Islam	124 (76.5)		5.65	
Buddhism	21 (13.0)		6.10	
Hindu	11 (6.8)		8.73	
Christian	6 (3.7)		6.67	
Marital status				0.000
Not Married	1 (0.6)		27.00	
Married	154 (95.1)		5.68	
Separated	4 (2.5)		10.00	
Widowed	3 (1.9)		7.67	
Number of children				0.306
1-3 children	113 (69.8)		6.28	
4-6 children	42 (27.8)		5.38	
More than 6	4 (2.5)		3.00	
Level of education				0.005
No formal education	2 (1.2)		17.00	
Primary	9 (5.6)		8.33	
Secondary	100 (61.7)		5.92	
Tertiary	51 (31.5)		5.16	
Household income				0.410
Below RM2,000	65 (40.1)		6.71	
RM2,000 to RM4,000	57 (35.2)		5.53	
RM5,000 to RM9,999	30 (18.5)		5.00	
RM10,000 and above	10 (6.2)		6.30	
Receiving help				0.354
Yes	96 (59.3)		6.26	
No	66 (40.7)		5.50	
Receiving depression treatment				0.001***
Yes	7 (4.3)		12.43	
No	155 (95.7)		5.66	

further investigation of the effect. The working status of participants was almost evenly distributed. Finally on the parents' demographic, 4 out of every 10 participants earned less than

RM2,000 monthly, 35.2% earned between RM2,000 to RM4,999 while 6.2% earned above RM10,000 monthly. Those who earned less than RM 2,000 and more than RM10,000

tended to have higher PHQ 9 scores relative to those who earned between RM2,000 to RM9,999. Nonetheless, this relationship was not statistically significant.

A total of 94% of the parents in the study were the primary carer of the patients. There are 59% submitted that they were receiving help from family and friends. Concurrently, 95.7% of the parents said they were currently not receiving treatment for depression. Table 1 also indicated that receiving depression treatment had an effect on the depression levels. Those who were already placed on depression treatment had a mean PHQ-9 score of 12.43 while parents who were not on depression treatment had a mean score of 5.66.

Regarding the children, their mean age and duration of illness was 7.2 years and 23 months respectively (Table 2). The children's age and duration of

illness had a negative relationship with the PHQ-9 score. The ratio of female to male children was 1:1.16. Regarding the types of cancer, 69% of the patients were diagnosed with leukemia, 7.4% were of brain and spinal cord tumors, 3.1% were of neuroblastoma and Wilms tumor respectively. In addition, 7 out of every 10 patients were currently on treatment while 27.2% had completed treatment. The parents whose children were still on treatment had almost twice as much as the PHO-9 scores of parents whose children had completed their treatment. The type of cancer also showed a significant effect on the PHQ-9 score, parents whose children had retinoblastoma had the highest PHQ-9 mean score (19.00) while parents whose children had germ cell neoplasm had the least PHQ-9 mean score (2.00).

Regarding the PHQ-9, 46.3% reported no depressive symptoms,

TABLE 2: Child demographics and mean PHQ-9 scores

Variable	N (%)	Mean PHQ-9	Mean (SD)	(Corr.) p-value
Child's age			7.20 (4.04)	(-0.056) 0.476
Duration of illness			23.08 (27.12)	(-0.130) 0.099
Child's Gender				0.430
Male	87 (53.7)	5.66		
Female	75 (46.3)	6.29		
Treatment Status				0.002
On treatment	118 (72.8)	6.69		
Treatment completed	44 (27.2)	3.95		
Diagnosis				0.030
Leukemia	112 (69.1)	6.1		
Brain and spinal cord tumor	12 (7.4)	5.50		
Neuroblastoma	5 (3.1)	5.00		
Wilm's tumor	5 (3.1)	5.00		
Lymphoma	8 (4.9)	4.88		
Retinoblastoma	1 (0.6)	19.00		
Bone cancer	8 (4.9)	9.75		
Germ cell neoplasm	5 (3.1)	2.00		
Other	6 (3.7)	3.17		

TABLE 3: Parents' PHQ-9 score frequencies by category

	N	%
No depression	75	46.3
Mild	59	36.4
Moderate	16	9.9
Moderately severe	8	4.9
Severe	4	2.5

36.4% were mild, and 9.9% of the parents had moderate depressive symptoms (Table 3). A total of 7.4% of the parents had moderately severe to severe depressive symptoms as they scored over 10 points in their PHQ-9 assessment. They were then confirmed to have MDD using the M.I.N.I.

Coping Strategies and PHQ-9 score

Using the Brief COPE Inventory, 14 coping strategies were identified. Aside from religion and substance use, other coping mechanisms increased depression levels, i.e., as the rank for these coping strategies increased

so did the parents' depression level increased (Table 4). However, only denial, behavioral disengagement, venting, instrumental support and self-blame were statistically significant.

Conversely, substance use and religion showed a negative relationship with the PHQ-9 scores of parents. The higher the ranking of these two factors the lower the parents' depression level. Interestingly, these two factors were not significant at 5% alpha level.

Predictive PHQ-9 Score with Significant Coping Strategies and Demographic Characteristics

Variables that were shown to have significant mean differences were included in the predictive regression analysis. Generally, the analysis of variance significance showed that age, marital status, level of education, depression treatment, patient treatment status and type of diagnosis were the only socio-demographic factors that affected the participants'

TABLE 4: Parents' coping strategies and relationship with PHQ-9 scores

Variables	Correlation	p-value
Self-distraction	0.051	0.523
Active coping	0.048	0.541
Denial	0.375	0.000***
Substance use	-0.063	0.427
Emotional support	0.133	0.090
Behavioural disengagement	0.381	0.000***
Venting	0.187	0.017**
Instrumental support	0.164	0.037**
Positive reframing	0.071	0.366
Self-blame	0.317	0.000***
Planning	0.033	0.673
Humour	0.075	0.346
Acceptance	0.020	0.799
Religion	-0.104	0.187

depression level at p<0.05. Due to insufficient samples for some of the categories, they were also dropped to avoid skewness of the results. On the other hand, five coping mechanisms (denial, behavioral disengagement, venting, instrumental support and self blame) had significant correlations with PHQ-9 among all the identified coping mechanisms.

Multiple regression analysis was used to test if income, depression treatment and four coping strategies significantly predicted participants' ratings of depression. The results of the regression indicated the four predictors explained 38.4% of the variance in PHQ-9 score (R2 =.376, F(8,153)=11.528, p<.00). It was found that denial significantly predicted depression level ($\beta = .517$, p<.027), behavioral disengagement ($\beta = 0.902$, p<.003), self-blame (β =0.747, p<.007), receiving depression treatment (B =3.960, p<.021) and treatment status of the child ($\beta = 2.335$, p<.002) (Table 5). Although the analysis revealed that older parents tended to have lower PHQ-9 scores, this finding was not significant at 0.05.

Prediction of the PHQ-9 score was stated in the following equation:

PHQ-9 score = -2.578 +(0.517 *Denial CM) + (0.902*Behavioral disengagement CM) + (0.294 *Venting CM) + (0.192 *Instrumental support CM) + (0.747 *Self blame CM) + (3.960 *depression treatment (Yes) + (2.335* Child treatment status (completed) - (0.059 *Age))

If a 35-year-old parent is chosen at random and has a score for the coping mechanism as follows; denial (4), behavioral disengagement (3), venting (5), instrumental support (5) and self-blame (3). Furthermore, if the parent is also currently receiving depression treatment, the child is still receiving cancer treatment, the PHQ-9 score can be estimated as:

PHQ-9 score = -2.578 +(0.517 *4) + (0.902*5) + (0.294 *3) + (0.192 *5) + (0.747 *5) + (3.960*1) + (2.335*1) -(0.059*35) = 13.81

This parent was predicted to have a PHQ-9 score greater than 10 and was

Variable	Estimate	SE	95% CI		p-value
			LL	UL	_
Denial	0.517	0.232	0.059	0.975	0.027**
Behavioural disengagement	0.902	0.300	0.309	1.496	0.003**
Venting	0.294	0.225	-0.150	0.738	0.192
Instrumental support	0.192	0.199	-0.202	0.586	0.337
Self blame	0.747	0.272	0.210	1.285	0.007**
Age	-0.059	0.047	-0.153	0.034	0.210
Treatment completed	2.335	0.740	0.873	3.796	0.059
On rreatment '	3.960	1.694	0.614	7.306	0.021**
Constant	-2.578	2.548	-7.612	2.456	0.313

TABLE 5: Regression estimates

classified to have a major depressive disorder.

Further Assessment in a Clinical Setting

While the validity and reliability of the PHQ-9 instrument have been termed adequate for the assessment of depressive symptoms amongst patients, the gap for misdiagnosing (either false negative or false positive) patients should not be left open. It is imperative to also assess patients in a clinical setting. In this study, the M.I.N.I. instrument was used to further investigate the parents' who scored more than 10 in the PHQ-9 assessment. The PHQ-9 threshold - 0 to 9 (none to moderate depression), and over 10 (moderately severe to severe depression) has been validated in several studies (Kroenke et al. 2001; Sherina et al. 2012).

Using the threshold, parents with more than 10 score were recruited for the M.I.N.I. The M.I.N.I. is a structured interview instrument that can be used to screen for psychiatric disorder in a clinical setting. The statistics distribution of PHQ-9 was presented below. All 12 parents who were categorised to have moderately severe to severe depression using the PHQ-9 instrument were also diagnosed with major depressive disorder with the M.I.N.I tool. This suggested that the overall rate of depression among parents of children with cancer in the two centers was 7.4% with a 95% confidence interval and a 2.5% margin of error.

DISCUSSION

The significant covariates in the study were age, patient's treatment status and receiving treatment for depression. The higher the duration and age of parents, the lower the PHQ-9 score. As the illness progresses, thedepression rate slows down. This is a type of adaptation that the parents have learnt over time. Parents begin to accept the situation and find a solution. In a study of depression among caregivers of patients with cancer in Turkey, it was shown that duration decreases the HADS-D (The Hospital Anxiety Depression Scale Depression)score of both the caregiver and that of the patients (Melloni et al. 2019; Unsar et al. 2021). However, this relationship was not significant as we found in the study too. The same study (Unsar et al. 2021) indicated that younger people tended to show more depressive symptoms. The results of this study showed that older parents had lower PHO-9 scores. Even with the difference in the assessment tools. the results from the previous studies and our study tended to align.

Newer research is now focusing on resilience and post-traumatic growth (PTG). While having a child with cancer appeared to be a significant source of stress that made one vulnerable to depression, we might have overlooked the resilience and psychological growth that these parents could have developed from the traumatic event. Both resilience and PTG conveyed the idea that adversity may bring positive changes instead, for example, better appreciation of life, improvement

interpersonal relationship enhancement of personal strength (Southwick et al. 2014; Tedeschi & Calhoun 2004). Studies have shown that parents of children with cancer did experience psychological growth following the illness of the children, and this positive change and resilience occurred more in this group of parents as compared to parents of children with other serious illness (Hungerbuehler et al. 2011; Oginska-Bulik & Ciechomska 2016; Phipps et al. 2015). Other studies demonstrated that people with higher levels of resilience were less susceptible to depression (Carvalho et al. 2016; Min et al. 2015; Ziaian et al. 2012). Hence, there was also a possibility that a good number of participants in our study had developed resilience and PTG, leading to a rather low prevalence of MDD among them. However, resilience and PTG were not measured here. New research focusing on these areas could bring new perspectives into this group of parents.

Many studies done among parents of children with cancer focused on psychological distress among these parents in general, and reported the prevalence to be around 11% to 55% (Ferrandis et al. 2008; Licková et al. 2021; Lakkis et al. 2016; Rosenberg et al. 2013). Comparatively, there were not as many studies done to elicit the rate of depression, particularly in regards to the diagnosis of MDD. The prevalence of MDD found among the parents of children with cancer in this study was 7.4%. This number was comparable to the prevalence of depression in Malaysia in general which was estimated to be between

8% and 12% (Ng 2014). However, if compared to other similar studies among parents of children with cancer done in other countries, the prevalence from our study appeared to be far less. For instance, both studies in Pakistan and Iraq reported the prevalence of depression among these parents to be as high as 70% (Al-Maliki et al. 2016; Ghufran et al. 2014) while Czech reported 11% (Licková et al. 2021). This prominent difference could be explained by the difference in the assessment tools used. The 2 studies used only screening tools to identify parents with depression, and the numbers were expectedly larger if compared to those parents who were eventually diagnosed and required treatment. Another possible explanation for the difference in prevalence was the difference in the settings of the study. The differences in cultural backgrounds, religion, support, expectations and healthcare delivery could all be contributory factors to the prevalence. Nevertheless, the lower rate found in our study showed that many parents have adopted several effective coping strategies with their children's illness.

The present findings suggested that parents with children who had a shorter duration since cancer diagnosis and who were still on treatment appeared to be more vulnerable to MDD. These results, despite not conclusive, were in keeping with the results of other studies carried out in similar participants. Parents experienced less distress and better quality of life when longer time had elapsed since the diagnosis of cancer for their children (Boman et al.

2003; Klassen et al. 2008; Norberg & Boman 2008; Phipps et al. 2015). This is most likely due to parental acceptance of the child's illness, with having made adjustments and adaptations made for treatment routines. Completion of treatment would also bring relief to the parents. Children who were still on treatment brought more distress to their parents compared to those who had completed treatment (Nakayama et al. 2017; Othman et al. 2011). Therefore, when screening for depression among the parents, we could monitor those who are at a higher risk for higher distress level. Marital status was found to be a possible risk factor for MDD as well in this study. This was unsurprising in view of marital status being wellknown for its association with MDD in general.

When comparing the strategies between groups with and without MDD, we found that both groups used religion the most as their coping strategies. This duplicated the finding of another study done in Malaysia among parents of children with acute lymphoblastic leukemia, where religion was the most frequently used methods of coping (Sherina et al. 2012). It showed that people often turned to religion when facing stressful situations. We also found that parents who used denial, a maladaptive coping strategy, more frequently had increased odds of having MDD. This finding was similar to the findings of previous studies in these parents where greater emotional distress was associated with the use of guilt and denial as coping behaviors (Ferrandis et al. 2008; Greening & Stoppelbein

2007). Hence, physicians should explore and discourage the utilisation of denial when attending to these parents. However, in our study, the direction of association between MDD and coping strategies could not be ascertained. The use of denial when faced with a stressful situation could be the consequences of suffering from MDD or a factor that predisposes a parent to MDD. Cohort studies could be carried out to look into this area.

The present study was the first done in Malaysia to examine the association between MDD and coping strategies amongparents of children with cancer. It also offered a current perspective into the prevalence of MDD among these parents. The major limitation of this study was the sample size. The limited number of cases with MDD identified in the study could affect the accuracy of the findings. Moreover, due to time and budget constraints, we only did convenience sampling which could have affected the validity of our study. Also, our study was only carried out in 2 settings which were among the major cities in Malaysia. This could lead to a limited generalisability of our findings. Future studies done on a larger scale, i.e. with a bigger sample size and involvement of more settings could be carried out to provide a better insight into this issue. In addition, the stigma associated with mental illness could introduce bias into our study. Parents who were depressed could have declined to participate, or provided answers that did not reflect the real situation that they were experiencing. This could have affected the prevalence that we

found. Similarly with the assessment of coping skills, where due to social desirability issues, parents would have selected coping strategies that appeared more adaptive, worrying of being judged. Nevertheless, properly-designed participants' information sheets, clear explanation and assurance of confidentiality when our study was carried out would have minimised this bias.

Screening of parents of children with cancer for depression should not be overlooked. While the majority of focus was put onto the child who was ill, the mental health of the parents was not insignificant. After all, it was the parents whom the children were very much dependent on. The care for the ill child would be jeopardised if the parent was not healthy, and the implications would be extended to other family members. Parents who were screened to be at high risk for depression by the pediatricians could then be referred to the psychiatric services for further evaluations and management. A psycho-education program for parents of pediatric cancer patients has been piloted in Malaysia with encouraging results (Othman 2010). An online caregiver education resource for Malaysian parents of children with leukemia or lymphoma has also been developed (Tan et al. 2023). In addition, physicians should be particularly attentive to those parents who utilise denial in coping with their children's condition in view of its association with MDD. We suggest that future research also explore the areas about resilience and PTG among this group of parents to

provide a local perspective into the possibility of positive aspects from a particularly traumatic event.

CONCLUSION

Parents of children with cancer should be screened for depression during this challenging time. This will enable early detection and intervention of depression. Continuous psychosocial support should also be provided for parents of children with cancer.

REFERENCES

- Alavian, R.S., Tabibi, Z., BaniHashem, A., AbdeKhodaei, M.S. 2015. Parent-child play therapy on depression symptoms in children with cancer decreases perceived stress on their mothers and improving parent-child relationship. *J Cell Immunother* 1(1-2): 4-5.
- Al-Maliki, S.K., Al-Asadi, J., Al-Waely, A., Agha, S. 2016. Prevalence and levels of depression among parents of children with cancer in Basrah, Iraq. *Sultan Qaboos Univ Med J* **16**(3): 329-34.
- Azizah, A.M., Nor Saleha, I.T., Noor Hashimah, A., Asmah, Z.A, Mastulu, W. 2016. Ministry of Health Malaysia. 2016. *Malaysian National Cancer Registry Report 2007-2011: Malaysia Cancer Statistics, data and figure*. https://www.crc.gov.my/wp-content/uploads/documents/report/MNCRRrepor2007-2011.pdf [8 March 2023].
- Boman, K., Lindahl, A., Bjork, O. 2003. Diseaserelated distress in parents of children with cancer at various stages after the time of diagnosis. *Acta Oncol* **42**(2): 137-46.
- Carvalho, I.G., Bertolli, E.D.S., Paiva, L., Rossi, L.A., Dantas, R.A.S., Pompeo, D.A. 2016. Anxiety, depression, resilience and self-esteem in individuals with cardiovascular diseases. *Rev Lat Am Enfermagem* **24**: e2836.
- Carver, C.S. 1997. You want to measure coping but your protocol's too long: Consider the brief COPE. *Int J Behav Med* **4:** 92.
- Carver, C.S., Scheier, M.F., Weintraub, J.K. 1989. Assessing coping strategies: A theoretically based approach. J Pers Soc Psychol 56(2): 267-83.
- Cernvall, M., Carlbring, P., Ljungman, G., Von Essen, L. 2013. Guided self-help as intervention

- for Traumatic stress in parents of children with cancer: Conceptualization, intervention strategies, and a case study. *J Psychosoc Oncol* **31:** 13-29.
- Creswell, P.D., Wisk, L.E., Litzelman, K., Allchin, A., Witt, W.P. 2014. Parental depressive symptoms and childhood cancer: The importance of financial difficulties. *Support Care Cancer* 22(2): 503-11.
- DOSM. 2020. https://www.dosm.gov.my/v1/index. php?. [17 March 2023]
- Elcigil, A., Conk, Z. 2010. Determining the burden of mothers with children who have cancer. *DEUHYO ED* 3(4): 175-81.
- Emerson, L.M., Bögels, S. 2017. A systemic approach to pediatric chronic health conditions: Why we need to address parental stress. *J Child Fam Stud* **26**: 2347-8.
- Ferrandis, E.D., Vaillo, Y.A., Garrido, M.J.G., Lopez, S.H., Soler, C.L. 2008. General distress, posttraumatic stress symptoms, and coping strategies in parents of children with cancer. *Temas Psicol* **16**(1): 47-61.
- Ghazali, S.A. 2021. Self-perceived depression, anxiety and stress among caregivers of cancer patients in Institut Kanser Negara, Putrajaya during Covid-19 Pandemic. http://eprints.usm.my/52025/1/Sarah%20Aqilah%20Ghazali-24%20pages.pdf
- Ghufran, M., Andrades, M., Nanji, K. 2014. Frequency and severity of depression among mothers of children with cancer: Results from a teaching hospital in Karachi, Pakistan. *Brit J Med Pract 7*(1): a701.
- Greening, L., Stoppelbein, L. 2007. Brief report: Pediatric cancer, parental coping style, and risk for depressive, posttraumatic stress, and anxiety symptoms. *J Pediatr Psychol* 32(10): 1272-7.
- Grootenhuis, M.A., Last, B.F. 1997. Adjustment and coping by parents of children with cancer: A review of the literature. *Support Care Cancer* 5(6): 466-84.
- Hungerbuehler, I., Vollrath, M.E., Landolt, M.A. 2011. Posttraumatic growth in mothers and fathers of children with severe illnesses. *J Health Psychol* **16**(8): 1259-67.
- James, K., Keegan-Wells, D., Hinds, P.S., Kelly, K.P., Bond, D., Hall, B., Mahan, R., Moore, I.M., Roll, L., Speckhart, B. 2002. The care of my child with cancer: Parents' perceptions of caregiving demands. J Pediatr Oncol Nurs 19: 218-28.
- Klassen, A.F., Klassen, R., Dix, D., Pritchard, S., Yanofsky, R., O'Donnell, M., Scott, A., Sung, L. 2008. Impact of caring for a child with cancer on parents' health-related quality of life. *J Clin Oncol* 26(36): 5884-9.
- Kostak, M.A., Avci, G. 2013. Hopelessness and depression levels of parents of children with cancer. Asian Pac J Cancer Prev 14(11): 6833-8.

- Kroenke, K., Spitzer, R.L., Williams, J.B.W. 2001. The PHQ-9: Validity of a brief depression severity measure. *J Gen Intern Med* **16**(9): 606-13.
- Lakkis, N.A., Khoury, J.M., Mahmassani, D.M.,
 Ramia, M.S., Hamadeh, G.N. 2016.
 Psychological distress and coping strategies in parents of children with cancer in Lebanon.
 Psycho-oncology 25(4): 428-34.
- Lam, C.G., Howard, S.C., Bouffet, E., Pritchard-Jones, K. 2019. Science and health for all children with cancer, *Science* **363**: 1182-6
- Licková, K., Čoček, A., Ambruš, M., Soumarová, R., Vránová, J., Klézl, P., Mitchell, A.J., Raudenská, J., Javůrková, A. 2021. Rapid screening of depression and anxiety in cancer patients: Interview validation of emotion thermometers. *Asian J Psychiatr* **65**: 102827
- Levis, B., Benedetti, A., Thombs, B.D., DEPRESsion Screening Data (DEPRESSD). 2019. Accuracy of patient health questionnaire-9 (PHQ-9) for screening to detect major depression: Individual participant data meta-analysis. *BMJ* 365: 11476
- Melloni, E.M.T., Poletti, S., Vai, B., Bollettini, I., Colombo, C., Benedetti, F. 2019. Effects of illness duration on cognitive performances in bipolar depression are mediated by white matter microstructure. J Affect Disord 249: 175-82.
- Min, J.A., Lee, C.U., Chae, J.H. 2015. Resilience moderates the risk of depression and anxiety symptoms on suicidal ideation in patients with depression and/or anxiety disorders. *Compr Psychiatry* **56**: 103-11.
- Nakayama, N., Mori, N., Ishimaru, S., Ohyama, W., Yuza, Y., Kaneko, T., Kanda, E., Matsushima, E. 2017. Factors associated with posttraumatic growth among parents of children with cancer. *Psychooncology* **26**(9): 1369-75.
- Ng, C.G. 2014. A review of depression research in Malaysia. *Med J Malaysia* **69:** 42-5.
- Norberg, A.L., Lindblad, F., Boman, K.K. 2005. Coping strategies in parents of children with cancer. *Soc Sci Med* **60**(5): 965-975.
- Norberg, A.L., Boman, K.K. 2008. Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety. Acta Oncol 47: 267-74.
- Oginska-Bulik, N., Ciechomska, M. 2016. Posttraumatic growth of parents struggling with cancer disease of their child – the role of rumination. *Adv Psychiat Neur* **25**(2): 99-110.
- Othman, A., Blunden, S., Mohamad, N., Mohd Hussin, Z.A., Jamil Osman, Z. 2010. Piloting a psycho-education program for parents of pediatric cancer patients in Malaysia. *Psycho-Oncol* 19(3): 326-31.
- Othman, A., Mohamad, N., Hussin, Z.A., Blunden, S. 2011. Psychological distress and associated factors in parents of children with cancer. *Int J*

- Soc Sci and Human 1(1): 37-42.
- Patel, J., Schraw, J.M., Lupo, P.J., Mian, A., Nembhard, W.N. 2020. Cancer risk by attained age among children with birth defects in Arkansas. *Cancer Epidemiol* 68: 101796.
- Phipps, S., Long, A., Willard, V.W., Okado, Y., Hudson, M., Huang, Q., Zhang, H., Noll, R. 2015. Parents of children with cancer: At-risk or resilient?. *J Pediatr Psychol* **40**(9): 914-25.
- Rajaratnam, S. 2013. Parental challenges in caregiving for children with cancer. [Master's thesis, Universiti Sains Malaysia]. http://eprints.usm.my/43966/1/SURENDRAN%20AL%20RAJARATNAM24.pdf
- Rosenberg, A.R., Dussel, V., Kang, T., Geyer, J.R., Gerhardt, C.A., Feudtner, C., Wolfe, J. 2013. Psychological distress in parents of children with advanced cancer. *JAMA Pediatr* 167(6): 537-43.
- Sheehan, D.V., Lecrubier, Y., Sheehan, K.H., Amorim, P., Janavs, J., Weiller, E., Hergueta, T., Baker, R., Dunbar, G.C. 1998. The mini-international neuropsychiatric interview (MINI): The development and validation of a structured diagnostic interview for DSM-IV and ICD-10. J Clin Psychiatry 59(Suppl 20): 20-33.
- Sherina, M.S., Arroll, B., Goodyear-Smith, F. 2012. Criterion validity of the PHQ-9 (Malay version) in a primary care clinic in Malaysia. *Med J Malaysia* **67**(3): 309-15.
- Southwick, S.M., Bonanno, G.A., Masten, A.S., Panter-Brick, C., Yehuda, R. 2014. Resilience definitions, theory, and challenges: Interdisciplinary perspectives. Eur J Psychotraumatol 5.
- Spitzer, R.L., Kroenke, K., Williams, J. B. 1999. Validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. JAMA 282(18): 1737-44.

- Sun, Y., Fu, Z., Bo, Q., Mao, Z., Ma, X., Wang, C. 2020. The reliability and validity of PHQ-9 in patients with major depressive disorder in psychiatric hospital. *BMC Psychiatry* 20(1): 474.
- Tan, C.E., Admodisastro, N., Lau, S.C.D., Tan, K.A., Teh, K.H., Lee, C.C., Mohd Sidik, S. 2023. Development and user evaluation of an online caregiver education resource for Malaysian parents of children with leukemia or lymphoma. *Asia Pac J Oncol Nurs* 11(2): 100363.
- Tang, W.P.Y., Chan, C.W.H., Choi, K.C. 2021. Factor structure of the brief coping orientation to problems experienced inventory in Chinese (Brief-COPE-C) in caregivers of children with chronic illnesses. *J Pediatr Nurs* 59: 63-9.
- Tedeschi, R.G., Calhoun, L.G. 2004. Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry* 15(1): 1-18.
- Unsar, S., Erol, O., Ozdemir, O. 2021. Caregiving burden, depression, and anxiety in family caregivers of patients with cancer. *Eur J Oncol Nurs* **50**: 101882.
- Warner, E.L., Kirchhoff, A.C., Nam, G.E., Fluchel, M. 2015. Financial Burden of Pediatric Cancer for Patients and Their Families. *J Oncol Pract* 11(1): 12-8.
- WHO, 2021. *Childhood cancer*. https://www.who.int/news-room/fact-sheets/detail/cancer-in-children. [18 February 2023]
- Yusoff, N., Low, W.Y., Yip, C.H. 2009. Reliability and validity of the Malay version of Brief COPE Scale: A study on Malaysian women treated with adjuvant chemotherapy for breast cancer. *Malaysian J Psy* **18**(1): 27-35.
- Ziaian, T., Anstiss, H., Antoniou, G., Baghurst, P., Sawyer, M. 2012. Resilience and its association with depression, emotional and behavioural problems, and mental health service utilisation among refugee adolescents living in South Australia. *Int J Popul Res* 1-9.