



“Use Positive Reframing, Not Behavioural Disengagement” Coping Strategy for Caregivers of Palliative Cancer Patients

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Abstract

Caregivers of palliative cancer patients (CPCP) who are depressed put both the patients and them at risk for serious physical and psychological complications. This study investigated the prevalence of depression and its contributing factors among the CPCP in Malaysia using the diagnostic tool and validated questionnaires. About 6% of CPCPs was diagnosed to have a major depressive disorder (MDD). Coping by ‘behavioural disengagement’ increased the odds for MDD while using ‘positive reframing’ was protective for MDD. The CPCP should be trained with beneficial types of coping strategy to help them reduce the burden of caregiving and to ensure optimum mental health status.

Keywords: Caregivers, Cancer, Palliative, Depression, Positive reframing, Disengagement

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1.0 Introduction

Cancer is a leading cause of death worldwide, accounting for an estimated 9.6 million deaths in 2018 (World Health Organization, 2018). In Malaysia, cancer is the fourth leading cause of death which contributes to 12.6% of all deaths in government hospitals and 26.7% in private hospitals (Ministry of Health, 2018). Patient with cancer experienced various physical, psychological, social and spiritual symptoms and difficulties. These affected not only the individual patient, but the Caregiver of Palliative Cancer Patients (CPCP) who manage daily care needs (Chirico et al., 2017; Richardson, Schüz, Sanderson, Scott, & Schüz, 2017; Teixeira, Applebaum, Bhatia, & Brandão, 2018).

The CPCPs are most often their spouse, adult child, relative, partner or friend and provide a broad range of unpaid assistance (Given, Sherwood, & Given, 2011). In Asian cultures, the family of CPCP assume caregiving roles out of obligation and filial piety (Funk et al., 2013). As cancer progresses and death grow closer, the needs of patients with cancer and their CPCPs intensify. Patients' dependency limit CPCPs' freedom and mobilisation, increase the feeling of exhaustion and fatigue and at the same time, reduce patients' functioning and responsibility of caregiving (Mahadevan et al., 2013). As a result, many CPCPs are more prone for emotional and psychological difficulties such as depression and anxiety (Fasse, Flahault, Brédart, Dolbeault, & Sultan, 2015; Pottie, Burch, Montross Thomas, & Irwin, 2014; Rumpold et al., 2016). In a recent systematic review and meta-analysis, about 42.3% of CPCPs were depressed (Wen et al., 2019).

Among family members of cancer patients, depression has been associated with specific factors such as younger age, female gender and spousal relationship, inadequate support received by the CPCPs and negative appraisals of caregiving demand (Teixeira et al., 2018). The CPCP level of burden also was found to be a predictor of depression and anxiety (Karabekiroğlu, Demir, Aker, Kocamanoğlu, & Karabulut, 2018; Wen et al., 2019). Often the CPCPs suffer from the burden of caring the patients at home, due to spending their time mostly around the patients and often neglecting their self-care and personal commitments (Ezat, Noraziani, & Sabrizan, 2012). The CPCPs of dying persons have also been identified as being at higher risk for health problems and increased mortality rates than the general population (Fredman et al., 2008; Parker Oliver et al., 2013; Perkins et al., 2013).

At the other spectrum of caregiving, there are also positive outcomes reported. The CPCPs have reported improved cognitive functioning and mood, caregiving-related enhancements in health, well-being and longevity, better relationship satisfaction and personal growth (Brown & Brown, 2014; Kang et al., 2013). Strengthening psychological and psychosocial resources can promote CPCPs' health (Applebaum & Breitbart, 2013; Fekete, Tough, Siegrist, & Brinkhof, 2017). Though studies exploring the role of coping and the association with caregiving and psychophysiological outcomes are lacking, coping strategies used by the CPCPs seem to influence their psychosocial adaptation and psychophysiological outcomes (Teixeira et al., 2018). For example, informal caregivers who used problem-based coping reported more regular exercise, have adequate sleep, less smoking or binge drinking, than those using emotion-focused coping (Litzelman, Kent, & Rowland, 2018). Through effective coping strategy, early palliative care approaches in symptoms management,

psychosocial care and spiritual support for the patient and families may improve quality of life (Estel et al., 2017). While several studies have been done to investigate coping strategy for the patients with palliative cancer treatment (Chirico et al., 2017; Richardson et al., 2017), studies to describe coping strategy of the CPCPs is still very limited. It is crucial to managing stress among the CPCPs to help reduce their emotional burden and identify their needs to ensure the health and better quality of life.

Currently, the gap is clear that sparse of knowledge on mental health status and coping style of the CPCPs to inform effective ways of managing stress related to the caregiving burden and its implications. Hence, this study aims to determine the prevalence of depression among the CPCPs and investigate its contributing factors, including how coping strategy associated with depression.

2.0 Material and Methods

This was a cross-sectional study to determine the prevalence of the depressive disorder among the CPCPs and its associated factors. It was carried out in a Palliative Cancer Clinic of one of the public hospitals in the northern state of Malaysia, which provides palliative care for more than 800 cases of cancer patients every year. Participants were selected using convenience sampling. The study included CPCPs who were attending the clinic and accompanying patients in the wards. The "CPCPs" was defined as the individual who self-declared her or himself as the person who had assumed the responsibility for caregiving of the palliative cancer patient. The CPCP may or may not be related to the patient, live with the patient, involved with decision-making regarding the patient. Those aged 18 to 65 years old, able to communicate fluently in *Bahasa Malaysia* or English and able to give informed consent were included in the study. We excluded those with a lack of mental capacity (mentally disturbed, intellectual disability, etc.).

The consented participants were given Proforma sociodemographic questionnaire, Multidimensional Scale of Perceived Social Support (MSPSS), Brief-COPE, Depression, Anxiety and Stress Scale-21 (DASS-21) and Mini International Neuropsychiatric Inventory (MINI). The Proforma sociodemographic data collected were the CPCPs' sociodemographic background, caregiving backgrounds and patients' background. Caregiving backgrounds include CPCPs' relationship to the patient, their status of living with patient, duration of caregiving, the voluntariness of caregiving, involvement in making the decision, history of training for caregiving and the presence of physical illness. Patients' background included age, duration of illness, presence and number of physical symptoms, number of admissions, Eastern Cooperative Oncology Group (ECOG) Score (scored by treating oncologist), self-care capabilities and hospice support.

The CPCPs' support was assessed using MSPSS, a 12-items Likert scale with a score from 1 (Strongly Disagreed) to 7 (Strongly Agreed) that measures social support perceived by the participant received from three specific sources either family, friends or significant others. The scale has been translated in Malay and validated with good internal consistency (Cronbach α of 0.89) (Ng, Siddiq, Aida, Zainal, & Koh, 2010). The CPCPs' types of coping were

measured with Brief-COPE, a 28 items Likert scale that measures 14 dimensions of coping strategy. It has been translated into Malay and validated with internal consistencies ranging from 0.51 to 0.99(Yusoff, Low, & Yip, 2009).

The CPCPs were also screened for depression using DASS-21, and those with positive results were then confirmed the diagnosis with MINI. DASS-21 has been translated into Malay and validated for depression, anxiety and stress(Musa, Fadzil, & Zain, 2007; Nordin, Kaur, Soni, Por, & Miranda, 2017). Moreover, MINI is a locally validated structured diagnostic interview instrument which was used to diagnose depressive disorder following the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5)(Mukhtar et al., 2012).

Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 23. Data were not normally distributed, hence nonparametric tests were used. Univariate and multivariate analyses were carried out to determine the significance of the association between depressive disorder and the various factors. The p-value of less than 0.05 with a confidence interval of 95% was taken as statistically significant.

Ethical approval was obtained from the Medical and Research Ethics Committee of National Clinical Research Center (CRC) Ministry of Health, Medical and Research Ethics ((5) KKM/NIHSEC/P17-910), Committee Faculty of Medicine Universiti Teknologi MARA, Medical and Research Ethics Committee, University Teknologi MARA (REC/171/17) and Medical and Research Ethics Committee Clinical Research Center (CRC) of the respective hospital prior to commencing the study.

3.0 Result

3.1 Depression among CPCPs

Initial screening with DASS indicated that 15(5%) of participants had mild to moderate depression; 19(9%) had mild to moderate anxiety, and 14(4%) had mild stress. The prevalence of the depressive disorder, diagnosed using MINI Major Depressive Disorder criteria among the participants was 6.1% (n=8).

3.2 Caregivers' Factors

• Sociodemographic Background.

A total of 141 CPCPs were enrolled in the study. The median (IQR) age group of the CPCPs was 42.00 (32.00) years. There were more female (81; 61.83%) than male (50; 38.17%) CPCPs were enrolled. The participants were predominantly Malays (110; 83.96%), married (90; 68.71%) and Muslim (110; 83.96%). Two third of them had below tertiary level education (87; 66.41%), half were unemployed (72; 54.96%) and the majority was at the lowest economic position (income below RM1310) (89; 67.9%). Refer to Table 1 for further sociodemographic characteristics of the CPCPs

Table 1: Caregivers' Sociodemographic Background in relation to Major Depressive Disorder

Variable	Major Depressive Disorder:n (%)			p-value
	Yes(n=8)	No (n=123)	Total (N=131)	
Age Group				
• 18-29	3 (2.29)	34 (25.95)	37 (28.24)	0.649 ^a
• 30-39	1 (0.76)	23 (17.55)	24 (18.32)	
• 40-49	1 (0.76)	21 (16.03)	22 (16.79)	
• 50-59	0 (0.00)	18 (13.74)	18 (13.74)	
• 60 and above	3 (2.29)	27 (20.61)	30 (22.90)	
Sex				
• Male	2 (1.52)	48 (36.64)	50 (38.17)	0.710 ^b
• Female	6 (4.58)	75 (57.25)	81 (61.83)	
Ethnic				
• Malay	6 (4.58)	104 (79.38)	110 (83.96)	0.080 ^a
• Chinese	0 (0.00)	13 (9.92)	13 (9.92)	
• Indian	1 (0.76)	5 (3.81)	6 (4.58)	
• Others	1 (0.76)	1 (0.76)	2 (1.52)	
Education Level				
• Non-tertiary	5 (3.8)	82(62.61)	87 (66.41)	1.000 ^a
• Tertiary	3 (2.3)	41(31.29)	44 (33.59)	
Occupation Status				
• Employed	2 (1.52)	57 (43.51)	59 (45.04)	0.294 ^b
• Unemployed	6 (4.58)	66 (50.38)	72 (54.96)	
Marital Status				
• Not Married	2 (1.52)	39 (29.77)	41 (31.29)	1.000 ^b
• Married	6 (4.58)	84 (64.12)	90 (68.71)	
Religion				
• Muslim	6 (4.58)	104 (79.39)	110 (83.96)	0.414 ^a
• Buddhist	1 (0.76)	12 (9.16)	13 (9.92)	
• Hindu	1 (0.76)	5 (3.82)	6 (4.58)	
• Christian	0 (0.00)	1 (0.76)	1 (0.76)	
• Others	0 (0.00)	1 (0.76)	1 (0.76)	
Income Group				
• RM 0-2000	8 (6.10)	101 (77.09)	109 (83.21)	0.351 ^b
• RM > 2000	0 (0.00)	22 (16.79)	22(16.79)	
Medical Illness				
• Yes	1 (0.76)	36 (27.48)	37(28.24)	0.440 ^b
• No	7 (5.34)	87 (66.41)	94(7185)	

^a Pearson Chi-square test and ^b Fischer's Exact test were used to compare the background characteristics of patients between those with and without depression. Significant p-value <0.05.

• **Caregiving Factors.**

Most of the CPCPs lived with the patient (105; 80.2%); less than half were the children (53; 40.46%), followed by spouse (37; 28.2%), parents (11; 8.39%) and siblings (3; 2.29%). Others were in-laws, relatives, friends or neighbours (27; 20.61%). Majority of the participants were physically healthy (94; 71.76%). The median (IQR) duration of taking care of the patient (since the cancer was first diagnosed) was 0.50 (1.90) years. Most of the CPCPs described that they took up caregiving by voluntary basis (123; 93.9%). More than half of the CPCPs stated that the patients made their own major decisions on their treatment (71; 54.2%). Majority of the CPCPs did not have any training on handling palliative cancer patients (118; 90.1%). There is no significant difference between the caregiving factors in relation to the diagnosis of depressive disorder. Refer to Table 2 for further details of the background caregiving factors.

• **Coping Strategy.**

Table 3 shows the 14 dimensions of coping strategy based on Brief-COPE and the differences between types of coping among the CPCPs who had and do not have a depressive disorder. The five most commonly used coping were religious coping, acceptance, active coping, positive reframing and the use of instrumental support.

• **Perceived social support.**

Based on MSPSS, overall by descending order, the participants perceived support came highest from the family (Med=5.50; IQR=2), followed by moderate support from significant others (Med=5.00; IQR=1.88) and moderate support from friends (Med=5.00; IQR=1.50). Overall the perceived total support among the CPCPs was noted to be high (Med=5.17; IQR =1.17).

Table 2: Caregiving Factors in relation to Major Depressive Disorder

Variable	Major Depressive Disorder		Total (N=131)	p-value
	Yes (n=8)	No		
Living with Patient				
• Yes	6 (4.58)	99 (75.57)	105(80.15)	0.658 ^b
• No	2 (1.52)	24 (18.32)	26 (19.85)	
Relationship to Patient				
• Parents	3 (2.29)	8 (6.11)	11 (8.39)	#
• Sibling	1 (0.76)	2 (1.52)	3 (2.29)	
• Spouse	1 (0.76)	36 (27.48)	37 (28.24)	
• Children	3 (2.29)	50 (38.17)	53 (40.46)	
• Others (neighbours, friends, in-laws, relatives)	0 (0.00)	27 (20.61)	27 (20.61)	
Major Decision Maker				
• Yes	2 (1.52)	58 (44.27)	60 (45.81)	0.288 ^b

Previous Training In	• No	6 (4.58)	65 (49.62)	71 (54.19)	
	• Yes	0 (0.00)	13 (9.92)	13 (9.93)	1.000 ^b
Voluntary CPCP	• No	8 (6.11)	110	118 (90.07)	
	• Yes	7 (5.34)	116	123 (93.89)	0.405 ^b
	• No	1 (0.76)	7 (5.34)	8 (6.11)	

Pearson Chi-square test and Fisher's exact test were not performed because the expected number in the cell less than 5.^b Fischer's Exact test was used to compare the background characteristics of patients between those with and without depression. Significant p-value <0.05.

3.3 Patients' Factors

• Patients' Background.

The patients' median (IQR) age was 63.00 (18.00) years. The median (IQR) duration of illness since first diagnosed with cancer was 2.00 (2.50) years. Age of patient was significantly different between those with and without depression (p=0.033). Majority complained of having physical symptoms (112; 85.49%), with median 2.00 (2.50) number of physical symptoms. Median (IQR) number of admissions was 1.00 (3.00) times since the time of diagnosis with cancer. Most of the patients had an ECOG score of 3 to 4, which indicated that the majority of the patients were capable only a limited self-care to none (80; 61.07%). Majority of the patients and CPCPs were not receiving hospice support (117; 89.31%).

• Patients' Clinical Factors.

The most common type of cancer is of the digestive organs (41; 31.29%), followed by breast (23; 17.55%) and female genital organ (13, 9.92%). Others were malignant neoplasms of lip, oral cavity and pharynx, urinary tract, lymphoid, hematopoietic and related tissue, male genital organs, mesothelium and soft tissue, thyroid and other endocrine glands, ill-defined, other secondary and unspecified sites, melanoma and other malignant neoplasms of skin and neoplasms of unspecified behaviour.

Table 3: Coping Strategy of the Caregivers in relation to Major Depressive Disorder

Rank	Coping Strategy	Major Depressive disorder		p-value
		Median (IQR)		
		Yes (n=8)	No (n=123)	
1	Religious	6.50 (4.00)	8.00 (1.00)	0.025*
2	Acceptance	4.00 (4.00)	7.00 (2.00)	0.058
3	Active coping	5.00 (3.00)	6.00 (2.00)	0.058
4	Positive reframing	3.50 (2.00)	6.00 (2.00)	0.003 *
5	Use of instrumental support	4.50 (4.00)	6.00 (3.00)	0.141
6	Planning	4.50 (3.00)	6.00 (2.00)	0.147
7	Use of emotional support	5.00 (3.00)	5.00 (3.00)	0.273
8	Self-distraction	4.00 (3.00)	4.00 (3.00)	0.876
9	Venting	5.00 (2.00)	4.00 (7.00)	0.100

10	Humour	3.00 (2.00)	4.00 (3.00)	0.286
11	Denial	3.00 (2.00)	2.00 (3.00)	0.837
12	Self-blame	4.50 (4.00)	2.00 (1.00)	0.034*
13	Behavioural disengagement	3.00 (5.00)	2.00 (0.00)	0.010 *
14	Substance use	2.00 (0.00)	2.00 (0.00)	0.539

Interpretation: 0-2.00: I have not been doing this at all; 2.01-4.00: I have been doing this a little bit; 4.01-6.00: I have been doing this a medium amount; 6.01-8.00: I have been doing this a lot; Mann-Whitney U test was used to compare the coping strategy between those with and without depression. Significant p-value <0.05.

Table 4: Background of the Patients in relations to Major Depressive Disorder

Variable	Major Depressive disorder: n (%)			p-value
	Yes (n=8)	No(n=123)	Total (N=131)	
Presence of Physical Symptoms				
• Yes	7 (5.34)	105 (80.15)	112 (85.49)	1.000 ^b
• No	1 (0.76)	18 (13.74)	19 (14.51)	
Hospice support				
• Yes	1 (0.76)	12 (9.16)	13 (9.92)	0.580 ^b
• No	7 (5.34)	110 (84.97)	117 (89.31)	
ECOG Score				
• 0	0 (0.00)	4 (3.05)	4 (3.10)	0.282 ^a
• 1	0 (0.00)	26 (19.84)	26 (19.84)	
• 2	3 (2.29)	16 (12.21)	19 (14.50)	
• 3	2 (1.52)	37 (28.24)	39 (29.77)	
• 4	3 (2.29)	38 (29.01)	41 (31.29)	
ECOG score based on self-care capabilities				
• 0-2	3 (2.29)	46 (35.11)	49 (37.40)	1.000 ^b
• 3-4	5 (3.81)	75 (57.25)	80 (61.07)	

^a Pearson Chi-square test and ^b Fischer's Exact test were used to comparing the background characteristics of patients between those with and without depression. Significant p-value <0.05.

3.4 Contributing factors of depression among CPCPs

Univariate analysis using Mann-Whitney U Test indicated that the coping strategy [behavioural disengagement (p=0.010), positive reframing (p=0.003), religious (p=0.025) and self-blame (p=0.034)], total perceived social support received by CPCPs (p=0.034) and patient's age (p=0.033) were associated with depressive disorder among the CPCPs. After controlling the confounding variables, logistic regression indicated that CPCPs' coping strategies were significantly associated with depressive disorder among the CPCPs include behavioural disengagement and positive reframing. The model was significant; Goodness of fit model by Cox & Snell R² is 18.0%, and Nagelkerke R² is 48.8%. The CPCPs who adopted the coping strategy of behavioural disengagement were likely to have a depressive disorder (p=0.04, OR=1.84, 95%CI=1.03-3.28), while CPCPs who adopted positive reframing coping

strategy were unlikely to have a depressive disorder ($p=0.03$, $OR=0.38$, $CI=0.15-0.93$). Refer to Table 5 for further details of the contributing factors.

Table 5: Contributing Factors for Depressive Disorder amongCPCPs

		B	S.E.	Wald	df	Sig.	OR	95% C.I.	
								Lower	Upper
Coping Strategy									
	• Behavioural disengagement	0.609	0.296	4.226	1	0.040*	1.838	1.029	3.283
	• Positive reframing	-0.982	0.463	4.490	1	0.034*	0.375	0.151	0.929
	• Religious	-0.442	0.322	1.887	1	0.170	0.643	0.342	1.208
	• Self-blame	0.286	0.380	0.565	1	0.452	1.331	0.632	2.800
Total perceived social support		0.670	0.565	1.404	1	0.364	1.954	0.645	5.918
Age of Patient		-0.084	0.046	3.286	1	0.070	0.920	0.840	1.007

Cox & Snell $R^2 = 0.180$, Nagelkerke $R^2 = 0.488$, $B = b$ coefficients, $S.E.$ = standard error, df = degree of freedom, * = statistically significant, OR = odd ratio, CI = confidence interval

4.0 Discussion

While patients with advanced cancer requiring palliative cares are dealing with their suffering and the illness, their CPCPs are experiencing stress, coping with their own personal issues as well as caring for the patients. These can bring to various psychological and physical challenges on top of concerns on death and dying issues. We found about 6% of CPCPs in this study had a major depressive disorder. This finding is higher than other multi-centre studies which also used similar diagnostic instrument in their study (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Using the Structured Clinical Interview for the DSM-IV (SCID), the authors found that only 4.5% of the CPCPs had a major depressive disorder. These findings, however, was lower than the percentage of depression in the general population (James et al., 2018). Perhaps, bereavement and caregiving those with cancer receiving palliative care alone may not contribute much to depression compared to other more stressful and well-known risk factors such as childhood neglect, trauma, and violence and acute life events (such as financial crisis)(Herrman et al., 2019).

To ensure the health of the patient and the CPCPs, both should have healthy coping strategies. Our study indicates that the best way for the CPCPs to cope with the stress and protect themselves from depression is by using positive reframing, supporting the previous findings found by other researchers (Litzelman et al., 2018). Having positive reframing type of coping encourages the CPCPs to analyse the situation and change their thought from 'seeing the glass half empty, to see the glass half full'. For example, "Wow—you have made it through four sessions of chemotherapy, and you only have four left!" (Eldridge, 2020). Positive reframing may not change the patients' illness condition totally, but it may undoubtedly reduce the negative perceptions and put things into a healthier viewpoint. In a review of psychological adaptation during the cancer experience, experts in psychology

indicated that psychosocial interventions (including positive reframing) might enhance the psychological and physiological adaptation indicators (such as neuroendocrine changes) in cancer patients. However, less is known about whether it may influence tumour activity, tumour growth-promoting processes, recurrence and survival rates of the patients (Antoni, 2013). In an interesting study among breast cancer patients, using positive reframing has been shown to reduce the stress experienced by both the patients and their partner (Robbins, Wright, María López, & Weihs, 2019). Furthermore, in a review study of caregiving, Marino, Haley, and Roth (2017) suggested that act of caregiving is perceived positive when the CPCPs feel satisfied and happy, have thoughts of having a purpose, meaning, and direction in life, have autonomous and self-acceptance thoughts while caring for the ill patient. These create constructive personal growth, positive relationship and sense of mastery of the challenges they are facing (Marino et al., 2017).

On the contrary, our study indicated that using behavioural disengagement type of coping may increase the chance of having a depressive disorder. This type of coping involves responses such as avoidance, denial, and wishful thinking; the style of diverting away from dealing with the stressor and/or its related emotions (Dijkstra & Homan, 2016). CPCPs with this type of coping acting as though the stressor (having cancer or its complication) does not occur, so that it does not have to be reacted to it, behaviourally or emotionally. On the other hand, he or she may have a fantasy (such as cancer may be cured by itself) which is damaging to the cancer patients (Carver & Connor-Smith, 2010). Several studies have shown that using this type of coping may result in more negative consequences of the stressor than other types of active coping strategies (Dijkstra & Homan, 2016). Supporting our study, experts in psychology who explored the multiple mediation effects of personal psychological resources between caregiving burden and depression in spousal CPCPs, agreed that by avoiding the stressor, the CPCPs had a higher tendency for depression (Khalaila & Cohen, 2016).

5.0 Conclusion

The findings of this research are relevant to inform authorities of the need for clinicians to address factors underpin depression among the CPCPs of palliative cancer patients. The type of coping used by the CPCPs should be addressed comprehensively to minimise caregiving burden, maintain the psychological and physical health of the CPCPs and to prevent complications. Enhancing knowledge of stress prevention through effective coping strategy and early detection of depression among CPCPs is crucial so that early and fast treatment and counselling can be offered to them. Together with coping strategies, the support system is equally essential to prevent depression among them. It is recommended that CPCPs who have depression to be given a chance to get access to effective treatment and rehabilitation.

This study provides insights to the contributing factors of depression and the role of coping strategies while providing caregiving among CPCPs of palliative cancer patients; nevertheless, we would like to inform that the study was limited by its design and suggest a more robust prospective study, and larger sample sizes to determine the causal factors for

depression among the CPCPs. We are aware that many other personal and environmental factors that could influence depression among them.

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