Self-reported psychological distress among caregivers of patients with cancer: Findings from a health facility-based study in Vietnam 2019

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Abstract

In Vietnam, little is elucidated in scientific literatures about the mental health of caregivers of people with cancer. We conducted a cross-sectional study to report the situation and correlates of self-reported psychological distress among caregivers of cancer patients in Vietnam in 2019. Multiple logistic and linear regression analyses were performed. A total of 16.5% of the study participants had psychological distress. Respondent's mean score of negative emotion was 7.6 \pm 2. Educational level and type of support were significantly associated with having psychological distress among caregivers. Gender, occupation, financial difficulty, treatment belief and social support significantly correlated to psychological distress level of caregivers.

Keywords

cancer, caregivers, psychological distress, Vietnam

Introduction

Cancer is a chronic disease that constitutes a significant proportion of the global burden of disease. According to the World Health Organization, cancer is currently the second most common cause of death in the world behind cardiovascular diseases. Patients diagnosed with cancer are forced to experience a long period of treatment and care which exerts adverse impacts on the physical, psychological, and practical aspects for not only the patients themselves, but also their caregivers (Glajchen, 2004). Additionally, in recent years, care for patients with cancer becomes more advanced and complex, including monitoring treatment, managing symptoms, supporting mental and emotional health, and assisting with individual care (Given et al., 2001). Therefore, the responsibilities of caregivers have been increasing, which may lead to an increase in their psychological pressure, psychological distress, and diminished mental health (Palos et al., 2011).

Previous studies have found caregivers of patients diagnosed with cancer experience high levels of depression and anxiety (Geng et al., 2018; Katende and Nakimera, 2017; Lee et al., 2013; Park et al., 2013; Rhee et al., 2008). The prevalence of depression and anxiety among family caregivers of patients with cancer were 42.3% (33.31, 51.29) and 46.56% (35.59, 57.52), respectively (Geng et al., 2018). Results from previous studies also show that factors related to depression and anxiety included caregiver characteristics

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such as age (Lee et al., 2013; Park et al., 2013), sex (Rhee et al., 2008), education level (Geng et al., 2018; Lee et al., 2015), occupation (Given et al., 2004; Lee et al., 2015; Park et al., 2013), relation to patient (Katende and Nakimera, 2017; Park et al., 2013; Rhee et al., 2008; Tang et al., 2007), self-efficacy (Lee et al., 2013), and patient characteristics such as age, gender (Dumont et al., 2006), symptoms (Dumont et al., 2006), recurrence, caregiving burden (Rhee et al., 2008), and quality of life (Park et al., 2013).

Vietnam is a low-middle income country located in the Southeast Asia region. In Vietnam, the age-standardized incidence rate of cancer was 151.4 per 100,000 people in 2018, corresponding to 164,671 new cancer cases (International Agency for Research on Cancer, 2019). In Vietnam, very little is elucidated in the scientific literature about the mental health of caregivers of patients diagnosed with cancer. Scientific evidence on this issue is crucial to health professionals in directing health planning and interventions both in Vietnam and similar settings in the world. Accordingly, we conducted this study to examine the situation and correlates of self-reported psychological distress among caregivers of cancer patients in Vietnam in 2019.

Study design

This research was conducted using a cross-sectional design.

Study participants

The participants of our study were caregivers of cancer patients, indicated by the patients as unpaid, nonprofessional care providers who were family members, distant relatives and meet the following criteria: (a) being a caregiver of cancer patients was diagnosed by the primary doctor, (b) age ≥ 18 years old, and (c) being physically and mentally capable to participate in the study, as determined by the trained research staff.

Study setting

The study was conducted in three major cancer hospitals of Ha Noi, Da Nang and Ho Chi Minh cities: Vietnam National Cancer Hospital (located in Tan Trieu), Ho Chi Minh Oncology Hospital, and Da Nang Oncology Hospital, respectively. The National Cancer Hospital is the leading tumor center in Vietnam with three branches, modern equipment and 2400-bed capacity, while Ho Chi Minh Oncology Hospital and Da Nang Oncology Hospital are the main cancer care centers in Central and Southern regions of Vietnam. In every hospital under investigation, three departments were selected as research sites, namely the Department of Radiation Oncology, Department of Abdominal Surgery and Department of Neurological Surgery.

Sample size and sampling

All caregivers of cancer patients who were treated at three above-mentioned departments of Cancer Hospitals from October 10th to October 25th, 2019 and met the eligibility criteria were included in this study.

Measurements

The dependent variables. Both self-reported prevalence and level of psychological distress among the caregivers of cancer patients were measured.

Psychological distress was identified if study participants reported that they experienced more than two symptoms of anxiety, frustration, or depression during the patient caregiving period (yes/no).

The level of psychological distress was evaluated by asking the study participants the score of their psychological symptoms (Score 0 = no symptom, Score 10 = highest level of symptom).

The independent variables. The socioeconomic characteristics of the participants were determined by assessing gender (male/female), caregiver age ($<45/\geq45$), education, occupation, relation (spouse/child/other), support, financial difficulty (yes/no), location (Ha Noi, Da Nang, Ho Chi Minh), knowledge, treatment belief and social support.

Educational level was grouped as: (a) incomplete secondary school (incompletion the ninth grade or no grade completion); (b) secondary school or higher (completion of ninth grade or higher).

Occupational status of the participants was categorized into two groups: (a) unemployed (without a paid job, including retirement or studying); (b) employed (currently working in a paid job).

Support of caregivers was categorized into three categories: (a) mainly support of both finance and care; (b) mainly support of finance or care; and (c) other (party supports in finance, care and/or different helps)

Knowledge was categorized by a response from caregivers (yes/no) of whether they had knowledge of cancer that the patient experienced.

Treatment belief of caregivers was identified by stated caregiver belief in the results of treatment (yes/no) for the patient who they take care of.

Social support of the carers was measured utilizing the Multidimensional Scale of Perceived Social Support (MSPSS) which consisted of 12 items determined level of social support from family, friends and significant others (Zimet et al., 1988). Each question was responded using 7-point Likert scale ranging from "very strongly disagree" (1) to "very strongly agree" (7). The sum of MSPSS scores ranged from 12 to 84. The following cut-offs were applied to group social support severity: low support (12–47),

moderate support (48–68), and high support (69–84) (Han et al., 2014). The questionnaire was translated into Vietnamese by a local expert, then another independent physician provided back-translation from those documents into English. Finally, a third professional translator compared both English versions to ensure consistency of content.

Data collection

Data collection was conducted through an individual interview by three interviewers in each hospital. The interviewers were research assistants trained by the principal investigator. The collectors reached carers during the patient's hospital attendance for screening, informed the information of the study, participants' rights and asking for involvement. The collectors then interviewed the caregivers who completed the informed consent to participate, following the study questionnaire for retrospective information. Data quality was controlled when conducting field work by the investigators of this study.

Data analysis and statistical methods

Both descriptive and analytical statistics were carried out using Stata 14 software (Stata Corporation).

Prevalence (%) of psychological distress and level of the problem (mean, median, minima, maxima, and standard deviation of psychological distress scores) among the study participants were calculated. Multivariate logistic regression modeling was performed to examine probability of having psychological distress in relation to sociodemographic status of the study respondents. Multivariate linear regression model was used to measure the correlates of scores of psychological distress among the caregivers. A significance level of p < 0.05 was used. Multiple imputation for missing data was performed following the recommendation of Sterne et al. (2009).

Results

Of the 730 caregivers of cancer patients invited, 704 agreed to participate and completed the survey (participation rate of 96.4%). Characteristics of the participants are shown in Table 1. The majority of caregivers were women (68.4%, n = 479), aged over 45 years old (57.7%, n = 406), and completed secondary or higher education (68.7%, n = 471). Overall, 92.7% (n = 625) of caregivers had a paid job. Almost half of them (47.0%, n = 327) were married to the patient, while 24.6% (n = 171) were children of the patient. Over 50% (n = 342) of the caregivers reported that they had supported the patient in both finance and care. Most respondents indicated the presence of financial burden (82.6%, n = 579).

When asked about cancer that patient experienced, 68.7% (n = 473) of caregivers confirmed that they were

Table I. General characteristics of the study caregivers.

Factor	Value
N	704
Sex	
Men	221 (31.6%)
Women	479 (68.4%)
Caregiver age	
<45	298 (42.3%)
≥45	406 (57.7%)
Education	
Incomplete secondary school	215 (31.3%)
Secondary school and higher	471 (68.7%)
Occupation	
Unemployed	49 (7.3%)
Employed	625 (92.7%)
Relation	
Spouse	327 (47.0%)
Children	171 (24.6%)
Others	198 (28.4%)
Support	
Finance and care	342 (50.1%)
Finance or care	221 (32.4%)
Others	119 (17.4%)
Financial difficulty	
Yes	579 (82.6%)
No	122 (17.4%)
Location	
Ha Noi	495 (70.3%)
Da Nang	96 (13.6%)
Ho Chi Minh	3 (6. %)
Knowledge	
Yes	216 (31.3%)
No	473 (68.7%)
Belief	
Yes	645 (93.2%)
No	47 (6.8%)
Social support	
Low support	203 (28.8%)
Moderate support	456 (64.8%)
High support	45 (6.4%)

not confident in the knowledge of the disease, while almost all caregivers (93.2%, n = 645) reported that they believed in the result of cancer treatment. 64.8% (n = 456) of caregivers received moderate social support, while 28.8% (n = 203) and 6.4% (45) of caregivers responded receiving low and high social support, respectively.

Table 2 presents the prevalence of psychological distress among the study caregivers. Over sixteen percent (16.5%) of the study participants had psychological distress. This proportion was higher among women than among men (17.3% vs 14.9%, p > 0.05). We observed a significantly higher psychological distress prevalence in participants who completed secondary school or higher

Table 2. Distribution of prevalence of negative emotion among the study caregivers.

	No	Yes	Total	p-value
n (%)	588 (83.5)	116 (16.5)	704 (100.0)	
Sex, n (%)				
Men, n (%)	188 (85.1)	33 (14.9)	221 (100.0)	0.43
Women, <i>n</i> (%)	396 (82.7)	83 (17.3)	479 (100.0)	
Caregiver age, n (%)				
<45, n (%)	255 (85.6)	43 (14.4)	298 (100.0)	0.21
≥45, n (%)	333 (82.0)	73 (18.0)	406 (100.0)	
Education, n (%)	, , ,			
Incomplete secondary school, n (%)	191 (88.8)	24 (11.2)	215 (100.0)	0.01*
Secondary school and higher, n (%)	381 (80.9)	90 (19.1)	471 (100.0)	
Occupation, n (%)				
Unemployed, n (%)	45 (91.8)	4 (8.2)	49 (100.0)	0.10
Employed, n (%)	517 (82.7)	108 (17.3)	625 (100.0)	
Relation, n (%)				
Spouse, n (%)	266 (81.3)	61 (18.7)	327 (100.0)	0.14
Children, n (%)	143 (83.6)	28 (16.4)	171 (100.0)	
Others, n (%)	174 (87.9)	24 (12.1)	198 (100.0)	
Support, n (%)				
Finance and care, n (%)	274 (80.1)	68 (19.9)	342 (100.0)	0.05
Finance or care, n (%)	188 (85.1)	33 (14.9)	221 (100.0)	
Others, n (%)	106 (89.1)	13 (10.9)	119 (100.0)	
Financial difficulty, n (%)		()		
Yes, n (%)	483 (83.4)	96 (16.6)	579 (100.0)	0.62
No, n (%)	104 (85.2)	18 (14.8)	122 (100.0)	
Location, n (%)		()		
Ha Noi, n (%)	400 (80.8)	95 (19.2)	495 (100.0)	0.01*
Da Nang, n (%)	89 (92.7)	7 (7.3)	96 (100.0)	
Ho Chi Minh, n (%)	99 (87.6)	14 (12.4)	113 (100.0)	
Knowledge, n (%)				
Yes, n (%)	185 (85.6)	31 (14.4)	216 (100.0)	0.29
No, n (%)	390 (82.5)	83 (17.5)	473 (100.0)	
Belief, n (%)		()		
Yes. n (%)	532 (82.5)	3 (7.5)	645 (100.0)	0.05
No. n (%)	44 (93.6)	3 (6.4)	47 (100.0)	
Social support, n (%)				
Low support, n (%)	172 (84.7)	31 (15.3)	203 (100.0)	0.68
Moderate support, n (%)	377 (82.7)	79 (17.3)	456 (100.0)	
High support, n (%)	39 (86.7)	6 (13.3)	45 (100.0)	

*The study caregivers were asked if they experienced any negative emotion during the course of taking care the patient (yes/no).

education compared to their corresponding group (19.1% vs 11.2%, p = 0.01). The percentage of caregivers experiencing psychological distress who provided both financial and direct care support was 19.9%, higher than that of those providing support only in finance or care (14.9%, 10.9%, p = 0.05).

Table 3 shows the summary statistic of negative emotion scores among the study caregivers. The respondents' mean score and SD of negative emotion was 7.6 ± 2.0 . That score was lower among men than women (7.4 ± 2.2 vs 7.7 ± 1.9). The caregivers who experienced financial problems reported a higher mean score of negative emotion than those without stated financial difficulty. The participants

who stated a belief in the treatment of patients had a negative emotion mean score lower than those without said beliefs (7.6 \pm 2 vs 8.4 \pm 1.6).

Table 4 illustrates the findings on factors associated with self-reported psychological distress among the caregivers of cancer patients in our study. Educational level and type of support were found to be significant correlates of having psychological distress among study caregivers (After controlling for other factors in the multivariable logistic regression model). As for educational level, study participants who completed secondary school and higher were approximately twice likely to have psychological distress than those who completed primary school (OR = 2.19, [95%]

Table 3. Summary statistics of negative emotion score* among the study caregivers.

	Mean	SD	Median	Min	Max
Sex					
Men (n=221)	7.4	2.2	8	0	10
Women (n=479)	7.7	1.9	8	0	10
Caregiver age					
<45 (n=298)	7.6	2	8	0	10
≥45 (n=406)	7.7	2	8	0	10
Education					
Incomplete secondary school (n=215)	7.5	2.2	8	2	10
Secondary school and higher $(n=471)$	7.7	1.9	8	0	10
Occupation					
Unemployed (n=49)	7.2	2.1	8	I	10
Employed $(n = 625)$	7.7	2	8	0	10
Relation					
Spouse (n = 327)	7.6	2.1	8	0	10
Children $(n = 171)$	7.4	2	8	0	10
Others $(n = 198)$	7.8	1.9	8	I	10
Support					
Finance and care $(n=342)$	7.7	2	8	0	10
Finance or care $(n=221)$	7.6	1.9	8	0	10
Others $(n = 9)$	7.5	2	8	I	10
Financial difficulty					
Yes $(n = 579)$	7.7	2	8	0	10
No $(n = 122)$	7.1	1.8	7	0	10
Location					
Ha Noi (<i>n</i> =495)	7.6	2	8	0	10
Da Nang (n=96)	7.6	1.6	8	4	10
Ho Chi Minh $(n = 3)$	7.7	2.1	8	I	10
Knowledge					
Yes (n=216)	7.5	2	8	0	10
No (n=473)	7.7	2	8	0	10
Belief					
Yes (n=645)	7.6	2	8	0	10
No (n=47)	8.4	1.6	9	4	10
Social support					
Low support $(n=203)$	7.8	2	8	I	10
Moderate support ($n = 456$)	7.6	2	8	0	10
High support (n=45)	7.4	2.3	8	I	10
Total (<i>n</i> = 704)	7.6	2	8	0	10

*The study caregivers were asked about level of negative emotion they experienced during the course of taking care the patient (score from 0 to 10).

CI: 1.33–3.59]). Caregivers who have other supports for cancer patients had significantly lower odds of having psychological distress as compared to those who mainly support cancer patients in both finance and care (OR = 0.47, [95% CI: 0.23–0.94]). Caregivers who were neither a spouse or child of cancer patients had lower likelihood of psychological distress than those who were the spouse of cancer patients; however, the difference was not statistically significant (OR = 0.64, [95% CI: 0.37–1.13]).

The results from the linear regression analysis of independent factors associated with level of psychological distress among the study caregivers are presented in Table 5. After controlling for other factors in the model, the noticeably significant association with psychological distress level among caregivers of cancer patients were gender, occupation, financial difficulty, treatment belief, and social support. Caregivers were more likely to have a higher level of psychological distress when they were female (coefficient 0.33, [95% CI: 0.001–0.65]); employed (coefficient 0.52, [95% CI: 0.04–1.01]) or did not hold a positive belief in the results of treatment process of cancer patients (coefficient 0.76, [95% CI: 0.16–1.35]). Caregivers who had no financial difficulty (coefficient -0.50, [95% CI: -0.89, -0.10]) or had high social support (coefficient -1.42, [95%

	Having psychological distress OR	[95% confidence interval]
Gender		
Men	1.00	[1.00, 1.00]
Women	1.24	[0.79, 1.98]
Caregiver age		
<45	1.00	[1.00, 1.00]
≥45	1.27	[0.76, 2.13]
Educational level		
Primary school	1.00	[1.00, 1.00]
Secondary school and higher	2.19**	[1.33, 3.59]
Occupation		
Unemployed	1.00	[1.00, 1.00]
Employed	1.14	[0.55, 2.36]
Relationship to patient		
Spouse	1.00	[1.00, 1.00]
Children	1.03	[0.55, 1.93]
Others	0.64	[0.37, 1.13]
Type of support		
Finance and care	1.00	[1.00, 1.00]
Finance or care	0.71	[0.44, 1.14]
Others	0.47*	[0.23, 0.94]
Financial difficulty		
Yes	1.00	[1.00, 1.00]
No	0.88	[0.50, 1.55]
Social support		
Low support	1.00	[1.00, 1.00]
Moderate support	1.30	[0.81, 2.09]
High support	1.45	[0.28, 7.39]
Treatment belief		
Yes	1.00	[1.00, 1.00]
No	0.31	[0.09, 1.06]
Knowledge		
Yes	1.00	[1.00, 1.00]
No	1.38	[0.87, 2.20]
Ν	704	-

Table 4. Logistic regression analysis of factors associated with having psychological distress among the study caregivers.

Coefficients; 95% confidence intervals in brackets.

*p<0.05. **p<0.01.

CI: -2.64, -0.21]) tended to have a lower level of psychological distress.

Discussion

To our knowledge, this is the first research on the psychological distress and related factors of caregivers of cancer patients in Vietnam. Caregivers play an important role in cancer treatment and management. Determining the situation of psychological distress and associated factors contributes to the process of prevention and control of mental health issues among caregivers and improve the quality of cancer treatment.

We found that 16.5% of the caregivers experienced psychological distress. The significant correlates of psychological distress among cancer carers were educational

level, type of support, and the belief of cancer treatment. Additionally, gender, occupation, financial difficulty, treatment belief, and social support were found to be significantly associated factors with psychological distress level of study caregivers.

Our findings on the prevalence of psychological distress are similar to the figure reported by Price et al. (2010) and Park et al. (2013) (ranging from 6% to 20%). In contrast, the prevalence of psychological distress in our study was generally lower than that reported in the studies of Braun et al. (2007) and Yang et al. (2012). This result can be interpreted from the different method we used to determine the psychological distress compared to these other studies.

Among the possible related factors of self-reported psychological distress in caregivers of cancer patients, we Gender Men

ciated with the psychological distress level among the study caregivers.		
Psychological distress level	coef. [95% confidence interval]	
0.00	[0.00, 0.00]	
0.33*	[0.001, 0.65]	
0.00	[0.00, 0.00]	
0.15	[_0 2 L 0 50]	

Table 5. Linear regression analysis of factors associated with the psychological distress level among the study caregivers

Women	0.33*	[0.001, 0.65]
Caregiver age		
<45	0.00	[0.00, 0.00]
≥45	0.15	[-0.21, 0.50]
Educational level		
Primary school	0.00	[0.00, 0.00]
Secondary school and higher	0.23	[-0.09, 0.56]
Occupation		
Unemployed	0.00	[0.00, 0.00]
Employed	0.52*	[0.04, 1.01]
Relationship to patient		
Spouse	0.00	[0.00, 0.00]
Children	0.00	[-0.44, 0.45]
Others	0.32	[-0.07, 0.71]
Type of support		
Finance and care	0.00	[0.00, 0.00]
Finance or care	-0.13	[-0.48, 0.22]
Others	-0.15	[-0.60, 0.30]
Financial difficulty		
Yes	0.00	[0.00, 0.00]
No	-0.50*	[-0.89, -0.10]
Social support		
Low support	0.00	[0.00, 0.00]
Moderate support	-0.16	[-0.50, 0.17]
High support	-1.42*	[-2.64, -0.21]
Treatment belief		
Yes	0.00	[0.00, 0.00]
No	0.76*	[0.16, 1.35]
Knowledge		
Yes	0.00	[0.00, 0.00]
No	0.05	[-0.28, 0.37]
Constant	6.81***	[6.08, 7.54]
N	704	_ –

95% confidence intervals in brackets.

*p < 0.05. ***p < 0.001.

found that high educational level (completed secondary school and higher) showed a statistically significant association with having psychological distress. This result is similar to previous findings (Geng et al., 2018; Sahadevan and Namboodiri, 2019). Additionally, financial and caregiving support was significantly associated with a higher likelihood of having psychological distress among cancer caregivers. This has not been demonstrated in any previous study. Several studies reported that younger age of caregivers was predictors of depression and anxiety among caregivers (Geng et al., 2018; Park et al., 2013). Meanwhile, our finding showed that caregiver age was not significantly associated with having psychological distress among cancer caregivers. This study has not explored the association between the relationship to the patients (not being the spouse or children of cancer patients) and psychological distress among caregivers, which appears to be a significant factor according to other literature (Park et al., 2013; Tang et al., 2007). In addition, a study conducted by Rhee (2008) found that female caregivers were more likely to experience depression than male; however, our study does not reproduce these results.

Regarding psychological distress level, our finding that higher social support was significantly correlated with a lower level of psychological distress, is consistent with findings of previous studies (Jeong and An, 2017; Karabekiroglu et al., 2018; Price et al., 2010). In this study, being female was a significant predictor of a higher level of psychological distress, similar to the findings of Burnette et al. (2017). However, this is not aligned with the finding from the previous study of Grov that there was no significant difference in the level of depression in either gender (Grov et al., 2005). Additionally, Given et al. (2004) found that caregivers who were employed were more likely to have a higher level of psychological distress in comparison to unemployed caregivers; this result is similarly demonstrated in our study. Our study participants who had no financial difficulty were less likely to have a higher level of psychological distress than those who had financial concerns. This is in line with previous findings (Park et al., 2013; Rhee et al., 2008). In addition, our findings indicate that caregivers who did not hold beliefs as to positive results of the treatment process of cancer patients tend to have a higher level of psychological distress. This is in accordance with the study result of Riley-Doucet (2005). In contrast, our study did not show certain factors such as caregivers' age, educational level, relationship to cancer patients, type of support and knowledge to be associated with higher levels of psychological distress. This is similar to the findings from previous research conducted in Uganda (Katende and Nakimera, 2017). This could be explained by the facts that in Vietnamese culture, performing a caregiving role to family members or relatives when health problems arise is considered an obvious obligation and a necessary responsibility as a social norm. In fact, many Vietnamese people perceived caregiving role to be rewarding rather than a burden.

There are several limitations to this study. Firstly, the cross-sectional study design does not permit for exploring the causality. Secondly, the convenience sampling technique used may lead to potential selection bias and could affect the generalizability of the research findings. In addition, the information of caregivers is self-reported, they were asked to respond their previous events. Therefore, systematic errors might establish during the data collection (recall bias). Finally, our findings might not be generalized to all caregivers of patients diagnosed with cancer, because this study is of hospital-based setting and also the clinical performance scores of different types of cancer patients were not collected to reflect the level of caregivers' psychological distress. It is essential to carry out further and well-designed studies exploring other characteristics that have impacts on the caregivers such as patient characteristics (cancer-related symptoms, mental health status, dependency. . .) care characteristics (duration, intensity, . . .), and caregivers characteristics (self-esteem, quality of relationship, finance status. . .)

Conclusion

In summary, we have demonstrated that psychological distress is prevalent among caregivers of cancer patients. Educational level and type of support were significantly associated with having psychological distress. Factors significantly correlated to psychological distress level of cancer caregivers were gender, occupation, financial difficulty, treatment belief, and social support. Appropriate public health interventions should be implemented to reduce caregiver psychological distress and enhance their quality of life to help improving patient care.

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Ethical considerations

The ethical approval of our study was obtained from the Institutional Review Board of Hanoi University of Public Health in Vietnam (Decision No. 424/2019/YTCC-HD3). Participation in this study was voluntary. All study participants were fully informed about the study objectives, the main content and their rights to withdraw at any time.

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