

Quality of end-of-life care of home-based care with or without palliative services for patients with advanced illnesses

Jui-Kun Chiang, MD, MSc^a, Yee-Hsin Kao, MD^{b,*}

Abstract

Palliative care has improved quality of end-of-life (EOL) care for patients with cancer, and these benefits may be extended to patients with other serious illnesses. EOL care quality for patients with home-based care is a critical problem for health care providers. We compare EOL quality care between patients with advanced illnesses receiving home-based care with and without palliative services.

The medical records of deceased patients who received home-based care at a community teaching hospital in south Taiwan from January to December 2019 were collected retrospectively. We analyzed EOL care quality indicators during the last month of life.

A total of 164 patients were included for analysis. Fifty-two (31.7%) received palliative services (HP group), and 112 (68.3%) did not receive palliative services (non-HP group). Regarding the quality indicators of EOL care, we discovered that a lower percentage of the HP group died in a hospital than did that of the non-HP group (34.6% vs 62.5%, P=.001) through univariate analysis. We found that the HP group had lower scores on the aggressiveness of EOL care than did the non-HP group (0.5±0.9 vs 1.0±1.0, P<.001). Furthermore, palliative services were a significant and negative factor of dying in a hospital after adjustment (OR=0.13, 95%CI= 0.05–0.36, P<.001).

For patients with advanced illnesses receiving home-based care, palliative services are associated with lower scores on the aggressiveness of EOL care and a reduced probability of dying in a hospital.

Abbreviations: CPR = cardiopulmonary resuscitation, ED = emergency department, EOL = end-of-life, ICU = intensive care unit.

Keywords: end-of-life, home-based care, palliative

1. Introduction

An aging population with an increasingly number of elderly people with disabilities has become a major problem in many countries, and the need for home-based and long-term care is growing rapidly.^[1] Home-based care is a part of a health care continuum. Patients receiving home-based care are generally considered homebound and may have multi-comorbidities,

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The datasets generated during and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

^{*} Correspondence: Yee-Hsin Kao, Department of Family Medicine, Tainan Municipal Hospital (Managed by Show Chwan Medical Care Corporation), 670 Chung Te Road, Tainan 70173, Taiwan (e-mail: m2200767@gmail.com).

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disabilities, and inadequate social support. This can cause such individuals to be frail and among the most vulnerable populations. A study reported that homebound patients had a greater risk of death, and their 2-year mortality was 40.3%.^[2] To improve the quality of care for homebound patients, home-based care is a fundamental medical service and should be integrated with long-term care for daily self-care services.

Taiwan became a country with an aged population in 2018, which is defined by the World Health Organization as a population with a proportion of >14% of people over 65 years old. The accelerating pace of population aging has triggered reforms of medical systems and policies. Taiwan's National Health Insurance (NHI) Administration launched the "Integrated Home Care" pilot project for home-based care and an integrated a new policy for long-term care to promote "aging in place" to address the challenges of an aging population.^[3] In Taiwan, a patient is qualified to apply for home-based care if they fulfill the following 3 criteria:

- 1. limited performance status (patient is bed-bound or chairbound for over 50% of the time awake),
- 2. definite medical or nursing care needs, and
- chronic conditions requiring long-term or continuous nursing care needs following hospital discharge.^[4]

Home-based care is reimbursed by the NHI program in Taiwan, and regulated parameters include the frequency of professional visits, including physician visits (once every 2 months) and nursing visits (once every 2 weeks).^[5]

Palliative care is an interdisciplinary and team-based approach to managing symptoms, providing psychological support, and

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^a Department of Family Medicine, Dalin Tzu Chi Hospital, Buddhist Tzu Chi Medical Foundation, Dalin, Chiayi, ^b Department of Family Medicine, Tainan Municipal Hospital (Managed by Show Chwan Medical Care Corporation), Tainan, Taiwan.

making treatment decisions for patients with serious illnesses and their families. Studies have highlighted that patients with cancer at the end-of-life (EOL) stage acquired numerous benefits from palliative care, including reduced symptom burden,^[6] improved quality of life and mood,^[7,8] improved caregiver outcomes,^[9] and better overall survival.^[8,10] These benefits can be extended to patients with other serious illnesses. In Taiwan, the use of palliative care has gradually progressed since 1983,^[11] and the palliative care system includes inpatient palliative care, hospice-shared care, and home palliative care. These palliative care types are covered by Taiwan's NHI program, and the scope of palliative care has been extended beyond cancer to 8 serious illnesses since 2009.

Studies have reported 6 accepted and validated quality indicators (QIs) of EOL cancer care, including:

- 1. receiving chemotherapy within 14 days of death,
- 2. having more than one emergency department visit during the last month of life,
- 3. being admitted to a hospital more than once during the last month of life,
- 4. receiving care in an intensive care unit (ICU) during the last month of life,
- 5. receiving cardiopulmonary resuscitation (CPR) during the last month of life, and
- 6. dying in a hospital.^[12-15]

In the current study, we omitted the indicator of receiving chemotherapy within 14 days of death, because this did not apply to serious patients without cancer. We used the other 5 QIs to evaluate the EOL care of home-based care patients.

Patients receiving EOL home-based care acquired several benefits including slightly increased patient satisfaction at a 1-month follow up,^[16,17] slightly reduced health care cost, fewer visits to outpatient clinics, a small reduction in inpatient days,^[18] and increased likelihood of dying at home.^[19] However, quality in the last month of life for patients with home-based care has seldom been investigated. The purpose of this study was to explore the quality of EOL care for patients receiving home-based care with palliative service group (HP group) and those without palliative service group (non-HP groups) to understand the role of palliative services.

2. Methods

We retrospectively reviewed patients who died of advanced illnesses who received home-based care at a metropolitan regional teaching hospital in Taiwan, between January 1 and December 31, 2019. The study protocol was approved by the institutional review board of the Tainan Municipal Hospital (Managed by Show Chwan Medical Care Corporation), Taiwan (SCMH_IRB No: 1090104).

2.1. Study participants

The criteria for patients to receive home-based care were mentioned above.^[4] Patients diagnosed with advanced illness with a prognosis of approximately 6-months of survival were eligible for palliative service. The assessment criteria applied in this study were in accordance with the Health Promotion Administration, Ministry of Health and Welfare regulations.^[20] The application of palliative service was assessed by the palliative care team. If patients with advanced illness require home-based palliative services, they might be transferred to palliative care team, and patients or their families often would like to sign donot-resuscitate form. The inclusion criteria for HP groups were patients received home-based care with palliative service and had signed do not resuscitate form, and those received home-based care without palliative service were classified in non-HP groups.

2.2. Data collection and definition of variables

The following information was derived from medical records: gender, age, major diseases (including cancer, chronic obstructive pulmonary disease, dementia, Parkinson disease, stroke, cirrhosis, end-stage renal disease, and congestive heart failure), invasive devices (such as a nasogastric [NG] tube, Foley catheter, and tracheostomy tube), total number of medication classes per day in the last month, drug integration between disciplines, total number of departments during outpatient visits, and site of death. Liquid drugs were defined as 1 class of medication, regardless of the amount. Clinical symptoms and signs of patients were collected during the first home visit. Body temperature was collected, and a fever episode was defined as a core temperature of $\geq 37.5^{\circ}$ C. For descriptive purpose, we categorized major diagnoses by using International Classification of Diseases, Tenth Revision, Clinical Modification codes. These categories included cancer (C00-C97), chronic obstructive pulmonary disease (J43 and J44), congestive heart failure (I50 and I50.x), end-stage renal disease on hemodialysis (Z99.2), dementia (F00, F00.x, F01, F01.x, F02, F02.x, and F03), Parkinson disease (G20 and G21.x), cirrhosis (K74.0, K74.60, and K74.69), and cerebrovascular accidents (stroke; I60-I68.x).

2.3. Study outcomes

Variables related to the QIs of EOL care were collected. The following 5 indicators of the quality of EOL care are:

- 1. having more than 1 emergency department (ED) visit,
- 2. being admitted to a hospital more than once,
- 3. receiving care in an ICU during the final month of life,
- 4. receiving CPR during the final month of life, and
- 5. dying in a hospital.

All these indicators were considered indicative of poor-quality care.

Then, the aggressiveness of EOL care was examined using a composite measure adapted from Tang et al.^[21] The scores ranged from 0 to 5, with higher scores indicating more aggressive EOL care.

2.4. Statistical analysis

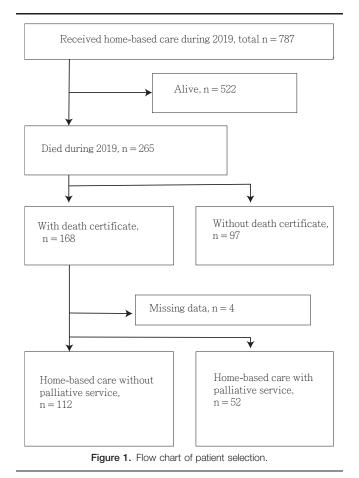
All statistical analyses were performed using R-3.6.1 (R Foundation for Statistical Computing, Vienna, Austria). A 2-sided *P* value of $\leq .05$ was considered statistically significant. The distributional properties of continuous variables are expressed as the mean \pm standard deviation and categorical variables by frequency and percentage. Normality was examined using the Shapiro–Wilk test. For the univariate analysis, the 2-sample *t* test, Wilcoxon rank-sum test, Chi-Squared test, and Fisher exact test were conducted to examine differences in the distributions of continuous and categorical variables between the HP and non-HP groups.

Multivariate analysis was conducted by fitting multiple logistic regression models with the stepwise variable selection procedure to determine vital predictors of QIs during the final month of life. Generalized additive models were fitted to detect the potential nonlinear effects of continuous covariates and determine appropriate cut off points to discretize continuous covariates, if necessary, during stepwise variable selection.

We assessed the goodness of fit of the final logistic regression model based on the estimated area under the receiver operating characteristic curve (also called the "*c* statistic"). In practice, a *c* statistic value (c=0-1) ≥ 0.7 suggests an acceptable level of discriminatory power. Statistical tools for regression diagnostics, including checking multicollinearity, were applied to ascertain any problems associated with the regression model or data.

3. Results

A total 265 patients receiving home-based care died between January 1 and December 31, 2019 were collected. After excluded no death certificate (n = 97) and missing data (n = 4), 164 patients receiving home-based care were included for analysis. Fifty-two (31.7%) patients received home-based care with palliative service (HP group), and 112 (68.3%) patients received home-based care without palliative service (non-HP group). Figure 1 depicted the study design. No significant differences were found among gender, number of drugs taken per day, number of departments during outpatient visits, and the integration of drugs between the HP and non-HP groups. The HP group was significantly younger



than the non-HP group $(79.0 \pm 11.1 \text{ vs } 84.2 \pm 9.6, P = .009)$. The HP group had a higher percentage of do-not-resuscitate orders than did the non-HP group [52 (100%) vs 76 (67.9%), respectively, P < .001] and died in institutions more [17 (32.7%) vs 8 (7.1%), respectively, P < .001; however, a lower percentage of the HP group died in hospitals than did the non-HP group [18 (34.6%) vs 70 (62.5%), respectively, P = .001; Table 1]. Regarding the clinical symptoms and signs of patients on the first day of enrollment, the HP group had a significantly higher percentage of fever, dyspnea, gastrointestinal (GI) bleeding, and vomiting than did the non-HP group. However, the HP group had a significantly lower percentage of unclear consciousness, NG tube use, and Foley catheterization use than did the non-HP group. The HP group also had significantly lower respiratory rates than did the non-HP group (Table 2).

By comparing the aggressiveness of care in the last month of life, the HP group was revealed to have a lower percentage of dying in the hospital than did the non-HP group [18 (34.6%) vs 70 (62.5%), respectively, P=.001], and the mean composite score for EOL care was lower than that of the non-HP group (0.5 ± 0.9 vs 1.0 ± 1.0 , respectively, P < .001). No significant differences were observed in ED visits, hospital admission, ICU admission, and CPR between the HP and non-HP groups (Table 3). Through multiple logistic regression analysis with adjustment, we discovered that palliative services were a significantly negative factor associated with dying in the hospital (OR 0.13, 95% CI: 0.05–0.36, *P* < .001). However, for the other QI, palliative care was not a significant factor. Dying in a hospital was a significantly positive factor associated with more than 1 hospitalization in the last month of life after adjustment (OR 9.98, 95% CI: 1.08-92.54, P=.043). Hospital stays were a significantly positive factor associated with more than 1 ED visit (OR 1.13, 95% CI: 1.07–1.19, P < .001), more than 1 hospitalization (OR1.23, 95% CI: 1.12–1.37, P<.001), ICU admission (OR 1.13, 95% CI: 1.03-1.23, P=.008), and CPR (OR 1.83, 95% CI: 1.03–1.36, P=.016) in the last month of life after adjustments. The area under the receiver operating characteristic curves all ranged from 0.835 to 0.941. All the models generally passed (Table 4).

4. Discussion

In the current study, we discovered that the mean composite score of the aggressiveness of the EOL was 0.8 ± 0.9 (scores ranged from 0–5), and receiving palliative services resulted in a lower score than not receiving palliative services. Another novel finding was that palliative services could reduce the probability of dying in a hospital.

A systemic review reported that patients receiving home-based care had an increased likelihood of dying at home,^[19] and a study reported that palliative care intervention enabled more patients to die at home.^[18] In the current study, we noted that 30.5% of patients receiving home-based care died at home, and patients receiving palliative services had a reduced probability of dying in a hospital, but this not enable more patients to die at home. One possible explanation was that patients with advanced illnesses received home-based care, and their families have sent them to nursing homes. The concept of death at home for the long-term care population and their families may change as these patients become older, develop more chronic conditions, become more likely to have dementia, and live in nursing homes for a long time.^[22–24]

The demographic data for patients with home-based care.

Variables	Total	Non-HP group, n (%)	HP group, n (%)	P valu
Number	164	112 (68.3%)	52 (31.7%)	
Gender				1
Male	83 (50.6%)	57 (50.9%)	26 (50.0%)	
Female	81 (49.4%)	55 (49.1%)	26 (50.0%)	
Age, yrs	82.5 ± 11.1	84.2±9.6	79.0 ± 11.1	.009
Major diagnosis				<.001
Cancer	64 (39.0%)	20 (17.9%)	44 (84.6%)	
Lung	12	2	10	
Colon and rectum	18	7	11	
Liver	15	2	13	
Stomach	4	1	3	
Others	15	8	7	
Non-cancer	100 (61.0%)	92 (82.1%)	8 (15.4%)	
COPD	10	7	3	
Dementia	32	28	4	
Parkinsonism	6	6	0	
Stroke	37	37	0	
Cirrhosis	2	1	1	
ESRD on hemodialysis	8	8	0	
CHF	5	5	0	
In the last month of life				
No. of medication classes per day	7.5 ± 3.3	7.4 ± 3.5	7.6 ± 2.9	.759
No. of departments during outpatient visits				.124
1	23 (14.0%)	16 (14.3%)	7 (13.5%)	
2	73 (44.5%)	44 (39.3%)	29 (55.8%)	
≥3	68 (41.5%)	52 (46.4%)	16 (30.8%)	
DNR, yes	128 (78.0%)	76 (67.9%)	52 (100%)	<.001
Site of death	()		× ,	
Home	51 (30.5%)	33 (29.5%)	17 (32.7%)	.717
Institution	25 (15.2%)	8 (7.1%)	17 (32.7%)	<.001
Hospital	88 (53.7%)	70 (62.5%)	18 (34.6%)	.001

HP group, non-HP group: Patients who received the home-based care with palliative service group were classified as HP group and those without palliative service group as non-HP groups. CHF = congestive heart failure, COPD = chronic obstructive pulmonary disease, DNR = do not resuscitate, ESRD = end-stage renal disease.

In current study, patients receiving home-based care had a mean composite score for the aggressiveness of EOL care of 0.8 ± 0.9 , and the score for patients receiving palliative services was 0.5 ± 0.9 . A study reported that the mean composite score for the

aggressiveness of EOL care for cancer patients was 2.04 ± 1.26 .^[21] Although the composite score for cancer patients ranged from 0 to 6 and 0 to 5 in the current study, patients undergoing home-based care received less aggressive in EOL care. A study

Table 2

Clinical symptoms and	l signs for patien	ts receiving home	e-based care.

		Non-HP group	HP group	
Variables	Total	n (%)	n (%)	P value
Conscious level, unclear	84 (51.5%)	65 (58.6%)	19 (36.5%)	.012
Systolic blood pressure (mm Hg)	127.5 ± 20.8	128.3 ± 20.5	125.8 ± 21.5	.475
Diastolic blood pressure (mm Hg)	71.8 ± 12.5	71.4±12.0	72.8 ± 13.4	.520
Pulse rate, times/min	89.1 ± 55.6	89.7 ± 66.2	87.7±19.5	.154
Respiratory rate, times/min	19.0 ± 5.8	19.8 ± 6.8	17.2±1.9	<.001
Pressure sore, yes	53 (32.5%)	39 (35.1%)	14 (26.9%)	.370
Fever (>37.5°C), yes	37 (22.7)	17 (15.3%)	20 (38.5%)	.002
Dyspnea, yes	30 (18.4%)	11 (9.9%)	19 (36.5%)	<.001
Gastrointestinal bleeding, yes	21 (13.0%)	10 (9.0%)	11 (21.6%)	.042
Vomiting, yes	12 (7.4%)	3 (2.7%)	9 (17.6%)	.002
Constipation, yes	62 (38.3%)	48 (43.2%)	14 (27.5%)	.058
Tube in patients				
Nasogastric tube	108 (65.9%)	86 (76.8%)	22 (42.3%)	<.001
Foley catheterization	73 (44.5)	61 (54.6%)	12 (23.1%)	<.001
Tracheostomy tube	4 (2.5%)	3 (2.7%)	1 (1.9%)	1

HP group, non-HP group: Patients who received the home-based care with palliative service group were classified as HP group and those without palliative service group as non-HP groups.

The comparison of the aggressiveness of care in the last month of life between non-HP grou	oup and HP group.
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Variables	Total No. (%)	Non-HP group No. (%)	HP group No. (%)	P value
Number	164	112 (68.3%)	52 (31.7%)	
\geq 2 ED visits	24 (14.6%)	18 (16.1%)	6 (11.5%)	.489
\geq 2 Hospitalizations	15 (9.1%)	12 (10.7%)	3 (5.8%)	.392
ICU admission	7 (4.3%)	7 (6.2%)	0	.099
CPR	3 (1.8%)	3 (2.7%)	0	.552
Dying in hospital	88 (53.7%)	70 (62.5%)	18 (34.6%)	.001
Score of aggressiveness of end-of-life care				.003
0	71 (43.3%)	37 (33.0%)	34 (65.4%)	
1	65 (39.6%)	53 (47.3%)	12 (23.1%)	
2	14 (8.5%)	11 (9.8%)	3 (5.8%)	
3	12 (7.3%)	9 (8.0%)	3 (5.8%)	
4	2 (1.2%)	2 (1.8%)	0	
Average (mean \pm SD)	0.8 ± 0.9	1.0 ± 1.0	0.5 ± 0.9	<.001

HP group, non-HP group: Patients who received the home-based care with palliative service group were classified as HP group and those without palliative service group as non-HP groups. CPR = cardiopulmonary resuscitation, ED = emergency department, ICU = intensive care unit.

reported that undergoing a home-based palliative care program resulted in lower hospital usage and lower health care costs.^[23] The NHI Administration launched the "Integrated Home Care" pilot project for health care. Home-based care may be transferred early on to home-based care with palliative services to improve EOL care in the last month of life.

A systemic review reported that homebound older patients receiving home-based primary care had a trend of reduction in ED visits (15%–20.8%), fewer hospitalizations (23%–84%), and fewer inpatient days (37.4%–49.9%).^[24] In the current study, we discovered that patients receiving home-based care had 0.8 ED visits and 7 inpatient days in the last month of life. In a study by North et al, 84 patients receiving home-based primary

care experienced 84% fewer hospitalizations (135 times per year) and 48% fewer ED visits (86 times per year).^[25] A study reported that home palliative care enabled patients with advanced lung cancer to have a 33.4% increased chance of dying at home and to have 8 fewer days in hospital stay in the last month of life compared with their counterparts who only received inpatient hospice care.^[26] A larger study sample is required to verify the association between patients receiving home-based care with palliative services and EOL care.

Understanding the symptoms of patients receiving home-based care is crucial for the patients to receive appropriate care. A systemic review reported that patients in their last 2 weeks of life had a weighted prevalence of symptoms, with 62.1% having

Table 4

The significant factors for the quality indicators by multivariate logistic regression for patients with home-based care in the last month of life.

Variables	\geq 2 ED visits	\geq 2 hospitalizations	ICU	CPR	Dying in hospital
Palliative service					0.13 (0.05–0.36)
Respiratory Rate					(<0.001) 0.73 (0.59–0.89) (0.002)
Hospital stay	1.13 (1.07–1.19) (<0.001)	1.23 (1.12–1.37) (<0.001)	1.13 (1.03–1.23) (0.008)	1.83 (1.03–1.36) (0.016)	()
Dyspnea		4.68 (0.98–22.33) (0.053)			
Times of ED visits					9.09 (4.32–19.14) (<0.001)
ESRD on hemodialysis					0.07 (0.01–0.52) (0.009)
Dying in a hospital		9.98 (1.08–92.54) (0.043)			(0.000)
Parkinsonism		(0.010)	21.16 (2.09–214.64)		
DNR			(0.010)	0.06 (0.004–0.93) (0.044)	
intercept	-3.05	-7.52	-4.90	-4.64	161
Nagelkerke R squared	0.254	0.534	0.279	0.373	0.518
Hosme-Lemeshow test	0.488	0.984	0.905	0.236	0.039
AUC (95% C.I.)	0.835 (0.770–0.900)	0.941 (0.902-0.981)	0.827 (0.669–0.984)	0.862 (0.600-0.100)	0.874 (0.815–0.933)

The values indicated: estimate (P value) (95%Cl).

CPR = cardiopulmonary resuscitation, DNR = do not resuscitate, ED = emergency department, ESRD = end-stage renal disease, ICU = intensive care unit.

dyspnea, 38.8% having fever, 31.0% having constipation, 19.4% having nausea/vomiting, 15.8% having pressure sores, and 11.9% having GI bleeding.^[27] In the current study, the prevalence of these symptoms was 18.4% with dyspnea, 22.7% with fever, 38.3% with constipation, 7.4% with nausea/vomiting, 32.5% with pressure sores, and 13.0% with GI bleeding. Patients receiving palliative services had more symptom burden such as with fever, dyspnea, GI bleeding, and vomiting did than those who did not receive palliative services. This may have been because cancer was the highest diagnosis for patients in the HP group (84.6%), and the home palliative care team could provide more frequent services for the HP group, once per week, than the once per month service that the non-HP group received.

Polypharmacy is the use of 5 or more medication classes and can result in inappropriate medical prescriptions, which can cause adverse drug events and lead to increased ED visits and hospitalization for older patients.^[28,29] A study reported that polypharmacy is prevalent in adults aged 65 years and older, with 40% taking 5 to 9 medications.^[30] In the current study, we noted that patients took approximately 7.5 medication classes daily during home-based care in the last month of life, and 41.5% of patients visited more than 2 departments during outpatient visits. We found that 3 cases (1.9%) may have been associated with adverse drug events, including hypoglycemia (1 case, sulfonylurea for diabetes), upper GI bleeding (1 case, apixaban for atrial fibrillation), and hypokalemia-related consciousness change (1 case, furosemide). Adverse drug events are key preventable causes of ED visits in older patients. Further study is warranted to investigate the association between ED visits and polypharmacy for patients receiving home-based care in the last month of life.

4.1. Limitations

Our study has several limitations. First, this study employed a retrospective medical record review, which has limitations inherent to this type of study design. Second, we examined the aggressiveness of EOL care by using a composite measure adapted from Tang et al.^[21] Further study is warranted to verify the results. Third, the prevalence of symptoms may have been underreported and underestimated because information was obtained from medical records. Finally, the sample size is limited to the number of patients included in the home-based care offered by our hospital.

5. Conclusion

Patients receiving home-based care and palliative services had lower scores regarding aggressive of EOL care and a reduced probability of dying in a hospital. Further study is warranted to verify the results with a larger sample size in future investigations.

Author contributions

Conceptualization: Jui-Kun Chinag, Yee-Hsin Kao. Formal analysis: Jui-Kun Chinag. Investigation: Yee-Hsin Kao. Methodology: Jui-Kun Chinag. Supervision: Yee-Hsin Kao. Validation: Yee-Hsin Kao. Writing – original draft: Yee-Hsin Kao. Writing – review & editing: Jui-Kun Chinag, Yee-Hsin Kao.

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