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ORIGINAL ARTICLE

A comprehensive approach in hospice shared care in Taiwan: Nonelderly patients have more physical, psychosocial and spiritual suffering



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Abstract While symptomatic differences exist between younger and older advanced cancer patients, few studies have examined the differences in their care with respect to age. Our goals were to examine the influences of age differences on physical, psychosocial and spiritual distress among advanced cancer patients. Advanced cancer patients who resided in Kaohsiung Medical University Hospital during 2007–2008 were recruited. Data were collected through professional consultants. The influences of age variations on physical, psychosocial and spiritual distress in nonelderly (<60 years old) and elderly (≥ 60 years old) patients were analyzed. A total of 1013 advanced cancer patients were included in the analyses with 467 nonelderly patients and 546 elderly patients. Nonelderly patients were identified to have a higher baseline pain level (4.0 vs. 2.8, $p < 0.001$), breakthrough pain (19.3% vs. 9.9%, $p < 0.01$), insomnia (6.4% vs. 2.7%, $p = 0.006$), emotional distress (69.0% vs. 60.6%, $p = 0.013$), and unwillingness to pass away because of concern for loved ones (18.8% vs. 11.9%, $p = 0.003$) with significant

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difference. Elderly ones were concerned about unfulfilled wishes (29.7% vs. 18.4%, $p < 0.001$) in spiritual concerns. After adjustments in regression models, nonelderly age (<60 years old) still revealed significant positive or negative impact on all categories of distress. Patients aged under 60 years have more physical, psychosocial and spiritual suffering. This study suggested that professional practitioners should provide intensive care for vulnerable terminally ill cancer patients.

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Introduction

Great advances in palliative care have been made in the past 10 years in Taiwan. The “quality of death” report from the Economist Intelligence Unit in 2010 suggested that Taiwan was ranked the 14th in the world and the highest among the Asian countries for the quality of end of life care [1]. However, our empirical works recognized some challenges in caring for nonelderly advanced cancer patients. Therefore, we conducted this research to identify the special needs of nonelderly cancer patients in terms of a comprehensive biopsychospiritual view in Taiwan.

Advanced cancer patients are distressed by troublesome suffering in the incurable metastatic stage [2]. Palliative care providers exert great efforts to provide comprehensive care for advanced cancer patients to improve their quality of life. In the literature, there are some variations in physical symptoms as well as psychological suffering between nonelderly and elderly cancer subjects [3–7]. Prior research also indicates that nonelderly patients have more spiritual distress as compared to elderly patients [8].

We aimed to provide the first comprehensive Asian analysis with regard to physical, psychosocial, and spiritual needs of advanced cancer patients specific to age variations in Taiwan. The literature has demonstrated an overt difference in physical symptoms between those individuals below and over 60 years of age [3,9,10]. Therefore, we used the age of 60 years as the cut-off value between nonelderly and elderly groups in this study. Furthermore, our society employs the Chinese calendar, which incorporates a system of heavenly stems and earth branches. In this cultural system, 60 years make a cycle termed “jiǎzǐ”, which is used to mean “a full lifespan”. People who have lived more than a jiǎzǐ are believed to be blessed.

Limited literature has been identified in researching psychosocial and spiritual characteristics in nonelderly advanced cancer patients in Taiwan. To our knowledge, no research has examined how age matters in advanced cancer patients in terms of a comprehensive view, including spiritual concerns. Better understanding of the age variations of cancer sufferings in advanced cancer patients will enhance the quality of palliative care.

Materials and methods

This study was approved by the Institutional Review Board of Kaohsiung Medical University Hospital, Taiwan. Advanced cancer patients who resided in Kaohsiung Medical University Hospital during the years 2007 and 2008 were recruited as our study participants. We defined advanced cancer patients as

having cancer which continued to progress, with metastases, and had a poor response to or was not suitable for curative treatment as judged by their cancer treatment physicians.

Data including demographic information, cancer types, metastatic sites, physical symptoms, awareness of diseases/prognosis, psychosocial problems, and spiritual distresses were collected by professional consultants (including a boarded palliative medicine physician and licensed hospice nurse). Cancer types and metastatic sites were obtained by chart review. Metastatic sites were recorded as “positive” according to image examinations and the consulting physician’s diagnosis. The professional consultants in this study were well-trained to evaluate physical–psychosocial and spiritual problems in advanced cancer patients. They administered detailed interviews as well as providing palliative consultation to these cancer patients. The contents of consultations included the most frequent psychosocial and spiritual concerns for these patients.

The collected information of physical symptoms included baseline pain level, breakthrough pain, delirium, weakness, anorexia, abdominal fullness, ascites, severe cough, edema, fungating tumor wound, dizziness/vertigo, pressure sore, infection, fever and insomnia. Pain level was measured by numerical rating scale (0–10 points, with a larger number representing a higher pain level).

Psychosocial problems including six major domains (awareness of disease/prognosis, emotional distress, difficulty in disease adaption, insufficient family support, inadequate financial support, and other psychological distress) were explored by professional consultants. “Awareness of disease/prognosis” meant that the patient clearly realized their cancer situation as well as its prognosis. “Emotional distress” was coded as categorized data, and emotional disturbance including anxiety, depression, sadness, and any other mood fluctuation were recorded as “yes”. Although validated scales would have been more accurate in mood distress screening, most advanced cancer patients were too weak to fill out a complicated questionnaire sheet. Therefore, we evaluated patients’ mood distress according to hospice professionals. “Difficulty in disease adaption” referred to patients who showed problems in disease acceptance, and it was recorded as categorized data.

The Hospice and Palliative Association designed and validated a special form for spiritual distress screening in Taiwan. This included six items of spiritual concerns (fear of death, doubt about existence, doubt about life meaning and death, after-death uncertainty, unfulfilled wishes, and unwillingness to pass away because of concern for loved ones). This questionnaire has been employed in most hospice wards in Taiwan for a number of years. All the information was collected at the beginning when the patients

were referred to hospice shared care consultants. In the spiritual domain, three items were demonstrated in our results including fear of death, unfulfilled wishes, and unwillingness to pass away because of concern for loved ones. Another three items (doubt about existence, doubt about life meaning and death, and after-death uncertainty) were questioned in the interview; however, they were eliminated from our results because of too few answers.

SPSS for Windows, version 14.0 (SPSS Inc., Chicago, IL, USA) was employed for statistical analysis. The level of statistical significance was set at 0.05 and all tests were two-tailed. Statistics used include frequencies, compared means (independent sample *t* tests were used to compare numerical variables) and χ^2 tests. Comparisons of primary cancer types, metastasis sites, physical, psychosocial, and spiritual variables among nonelderly (<60 years old) patients and elderly patients (≥ 60 years old) were analyzed to identify variations between different age groups. Furthermore, multiple logistic regression was employed to analyze the influences of age accompanying demographic and medical factors on physical, psychosocial and spiritual factors.

Results

A total of 1013 advanced cancer patients were recruited for this analysis. The demographic variations among the two age groups (younger than 60 years vs. 60 years and above) are demonstrated in Table 1. There were 467 patients (46.1%) in the nonelderly group with a mean age of 49.2 ± 7.9 years, and 546 patients (53.9%) in the elderly group with a mean age of 72.2 ± 8.4 years. Comparisons of cancer sites and metastasis showed that head and neck cancer, respiratory tract cancer, hepatobiliary cancer,

breast cancer, and urinary tract cancer presented group differences with statistical significance. Head and neck cancer and breast cancer were more likely to occur in the nonelderly group, which is different from most other cancer types. Head and neck cancer ranked the highest in the nonelderly group (30.2%). Concerning metastatic sites, bone metastases tended to occur more frequently in the nonelderly group (31.0%).

Cancer-related physical symptoms in these two groups are shown in Table 2. Nonelderly subjects were more likely to suffer from higher baseline pain level as well as more breakthrough pain with statistical significance. Prevalence of breakthrough pain was 19.3% in the nonelderly group, and 9.9% in the elderly group. A higher prevalence in the nonelderly group than in the elderly group was also noted in fungating tumor wound, dizziness, and insomnia with statistical significance. However older patients suffered more from anorexia, leg edema and pressure sores, which occurred more frequently in the elderly group.

Psychosocial and spiritual issues are demonstrated in Table 3. We compared six psychosocial problems and three spiritual problems that the majority of advanced cancer patients experienced in Taiwan. Nonelderly patients had higher prevalence (69.0%) in emotional distress experience than elderly patients (60.6%) with statistical difference ($p = 0.013$). In contrast, elderly patients (44.1%) were unaware of their diagnosis/prognosis compared with the nonelderly group, with statistical significance.

Regarding spiritual issues, the fear of death, unfulfilled wishes, and unwillingness to pass away because of concern for loved ones were three domains out of six items of the questionnaire that were identified to have statistical significance in our study. These three concerns ranked as the most important that advanced cancer patients in Taiwan

Table 1 Demographic comparison of participants between nonelderly and elderly groups.

Demographic characteristics	Age stratification		<i>p</i>
	<60 y <i>n</i> = 467	≥ 60 y <i>n</i> = 546	
Age (y) (mean \pm SD)	49.2 \pm 7.9	72.2 \pm 8.4	<0.001 ^a
Gender (male)	325 (69.6%)	330 (60.4%)	0.002
Cancer type and site			
Head and neck	141 (30.2%)	61 (11.2%)	<0.001
Gastrointestinal tract	100 (21.4%)	105 (19.2%)	0.390
Respiratory tract	47 (10.1%)	115 (21.1%)	<0.001
Hepatobiliary	68 (14.6%)	117 (21.4%)	0.005
Pancreatic	13 (2.8%)	21 (3.8%)	0.385
Breast	32 (6.9%)	19 (3.5%)	0.02
Gynecological	23 (4.9%)	22 (4.0%)	0.542
Urinary tract	7 (1.5%)	37 (6.8%)	<0.001
Hematology	13 (2.8%)	20 (3.7%)	0.481
Metastatic site			
Lung	108 (23.1%)	96 (17.6%)	0.034
Liver	104 (22.3%)	136 (24.9%)	0.336
Bone	145 (31.0%)	136 (24.9%)	0.035
Brain	52 (11.1%)	55 (10.1%)	0.609

% out of age stratifications.

^a A *t* test was used for analysis; Chi-square analysis was used for other variables.

Table 2 Comparison of physical symptoms between nonelderly and elderly groups.

Physical symptoms	Age stratification				<i>p</i>
	<60 y		≥60 y		
	<i>n</i> = 467		<i>n</i> = 546		
Baseline pain level	4.0 ± 3.0		2.8 ± 2.8		<0.001 ^a
Weakness	454	(97.2%)	520	(95.2%)	0.140
Anorexia	342	(73.2%)	440	(80.6%)	0.007
Abdominal fullness	186	(39.8%)	250	(45.8%)	0.057
Leg edema	127	(27.2%)	186	(34.1%)	0.02
Infection	93	(19.9%)	105	(19.2%)	0.812
Breakthrough pain	90	(19.3%)	54	(9.9%)	<0.001
Ascites	88	(18.8%)	102	(18.7%)	0.999
Fungating tumor wound	64	(13.7%)	28	(5.1%)	<0.001
Fever	49	(10.5%)	49	(9.0%)	0.456
Delirium	48	(10.3%)	73	(13.4%)	0.837
Severe cough	31	(6.6%)	33	(6.0%)	0.7
Insomnia	30	(6.4%)	15	(2.7%)	0.006
Dizziness	16	(3.4%)	4	(0.7%)	0.003
Pressure sore	12	(2.6%)	33	(6.0%)	0.009

% out of age stratifications.

^a *t*-test was used for analysis; Chi-square analysis was used for other variables.

suffered from. Among these three domains, the most common distress that patients in both groups experienced was fear of death. Nonelderly patients were more likely to suffer from "unwillingness to pass away because of concern for loved ones" (18.8%) compared with 11.9% in the elderly group which was a statistically significant difference ($p = 0.003$). Elderly patients, however, were more concerned about unfulfilled wishes (29.7%) than nonelderly patients (18.4%) with statistical significance ($p < 0.001$).

The impact of age on symptomatic differences may be confounded by other factors. Therefore, we analyzed the influences of physical factors on psychosocial or spiritual factors by multiple logistic regressions. The results are demonstrated in Tables 4 and 5. After adjustment,

nonelderly age (<60 years old) still revealed a significant positive or negative impact on psychosocial and spiritual suffering. Moreover, the positive or negative correlation was consistent with comparison analysis: nonelderly age (<60 years old) was related to higher frequency of breakthrough pain [odds ratio (OR) 1.61], emotional distress (OR 1.32), and unwillingness to pass away because of concern for loved ones (OR 1.99). In contrast, elderly age was related to unawareness of disease/prognosis (OR 0.46) and unfulfilled wishes (OR 0.64). In addition to young age, female gender also has a significantly greater risk in emotional distress (OR 1.50). Morphine use for cancer pain revealed less risk of breakthrough pain (OR 0.51), anorexia (OR 0.39) and emotional distress (OR 0.53).

Table 3 Comparison of psychosocial and spiritual distress between nonelderly and elderly groups.

Psychosocial and spiritual distress	Age stratification				<i>p</i>
	<60 y		≥60 y		
	<i>n</i> = 467		<i>n</i> = 546		
Psychosocial issues					
Unawareness of disease and prognosis	115	(24.6%)	241	(44.1%)	<0.001
Emotional distress	322	(69.0%)	331	(60.6%)	0.013
Difficult in disease adaption	349	(74.7%)	424	(77.5%)	0.239
Insufficient family support	20	(4.3%)	17	(3.1%)	0.505
Inadequate financial support	14	(3.0%)	6	(1.1%)	0.070
Other psychosocial problems	29	(6.2%)	33	(6.0%)	0.606
Spiritual issues					
Fear of death	162	(34.7%)	205	(37.5%)	0.230
Having unfulfilled wishes	86	(18.4%)	162	(29.7%)	<0.001
Concern for loved ones ^a	88	(18.8%)	65	(11.9%)	0.003

% out of age stratifications.

Chi-square analysis was used in this table.

^a Unwillingness to pass away because of concern for loved ones.

Table 4 Influence of age (<60 y) plus demographic and medical factors on metastases and physical symptoms in advanced cancer patients.

Demographic and medical factors	Metastases and physical symptoms			
	Bone metastasis	Lung metastasis	Breakthrough pain	Anorexia
<60 y	1.65 (1.21–2.24)**	1.43 (1.03–1.99)*	1.61 (1.09–2.38)*	0.59 (0.43–0.82)**
Gender (female)	0.71 (0.50–0.99)*	0.89 (0.62–1.29)	1.04 (0.68–1.61)	1.05 (0.74–1.50)
Head and neck cancer	0.53 (0.34–0.83)**	0.33 (0.20–0.54)**	1.44 (0.92–2.26)	0.43 (0.29–0.64)**
Respiratory tract cancer	3.52 (2.43–5.10)**	0.27 (0.14–0.50)**	0.48 (0.25–0.95)*	0.57 (0.37–0.87)*
Breast cancer	9.61 (4.89–18.91)**	4.26 (2.26–8.06)**	1.06 (0.44–2.56)	1.15 (0.52–2.54)
Bone metastasis	–	–	0.94 (0.61–1.45)	1.26 (0.88–1.81)
Morphine use	–	–	0.51 (0.34–0.75)**	0.39 (0.26–0.58)**

All results are presented as odds ratios and the intervals of 95% confidence are presented in parenthesis.

*Significant at 5% level.

**Significant at 1% level.

Discussion

This is the first study to describe the physical, psychosocial and spiritual needs of nonelderly advanced cancer patients in Taiwan. Our findings indicated that nonelderly cancer patients suffered more from pain, fungating tumor wound, insomnia, dizziness, emotional distress, and unwillingness to pass away because of concern for loved ones. The impact of age on symptomatic differences remains great and is significant after adjustment. Palliative care emphasizes comprehensive care, which provides relief for physical symptoms as well as psychological and spiritual suffering [11]. Therefore, palliative professional consultants should notice these characteristics in nonelderly advanced cancer patients and provide more individualized and tailored palliative care plans.

Higher baseline pain level and more frequent breakthrough pain were identified in nonelderly cancer patients in the present study. The literature generally supports this observation. Cheung et al. are in agreement with our finding that younger patients reported worse pain [3]. Although Green et al. indicated no significant differences in pain severity between different age groups [12], they identified more pain flares in younger patients. Svendsen et al. demonstrated that higher frequencies of breakthrough pain were

reported in developed countries than in developing ones [13]. Significant physical and psychological burdens caused by breakthrough cancer pain may result in a severely diminished quality of life in the limited life expectancy of advanced cancer patients. Uncontrolled pain is a major factor in vulnerability to suicide in patients with advanced cancer [14]. Our findings suggested that morphine use was associated with less breakthrough pain and less emotional distress. This trend is compatible with the literature. We advocate that palliative care providers should pay great attention to nonelderly patients with advanced cancer regarding the pain level and breakthrough pain, especially in Asian populations where pain levels may be under-reported.

Head and neck cancer was more prevalent in nonelderly patients according to our results. An official government report demonstrated that the most common malignancy in the 25–44-year-old male population in Taiwan is oral cancer, and its incidence is increasing rapidly [4]. Oral cancer (95%) accounts for most head and neck cancer in the present study. Oral cancer prevalence differs between eastern (about 40% of all cancers) and western countries (less than 5%) [15,16]. The habit of betel nut chewing in some of our country's population may explain this feature [15]. Goldstein et al. advocated the importance of the interdisciplinary team in the care of head and neck cancer patients

Table 5 Influences of age (<60 y) plus demographic and medical factors on psychosocial and spiritual symptoms in advanced cancer patients.

Demographic and medical factors	Psychosocial and spiritual symptoms			
	Unawareness of disease/prognosis	Emotional distress	Having unfulfilled wishes	Concern for loved ones
<60 y	0.46 (0.35–0.62)**	1.32 (1.00–1.74)*	0.64 (0.47–0.88)*	1.99 (1.37–2.88)*
Gender (female)	0.90 (0.66–1.21)	1.50 (1.11–2.03)*	0.86 (0.62–1.20)	0.75 (0.50–1.13)
Head and neck cancer	1.12 (0.77–1.63)	1.25 (0.87–1.81)	0.76 (0.49–1.17)	0.85 (0.52–1.37)
Respiratory tract cancer	1.38 (0.95–2.01)	0.87 (0.60–1.27)	1.10 (0.73–1.65)	1.36 (0.82–2.25)
Breast cancer	0.47 (0.21–1.07)	0.60 (0.31–1.16)	1.03 (0.48–2.19)	1.48 (0.61–3.56)
Bone metastasis	1.38 (0.99–1.91)	0.77 (0.56–1.06)	1.24 (0.87–1.78)	1.79 (1.13–2.84)*
Morphine use	1.44 (1.03–2.01)*	0.53 (0.39–0.72)**	1.83 (1.23–2.70)*	1.44 (0.93–2.24)

All results are presented as odds ratios and the intervals of 95% confidence are presented in parenthesis.

*Significant at 5% level.

**Significant at 1% level.

[17]. Occurrence of younger age, malignant fungating wound, intractable neuropathic pain caused by tumor compression or invasion, facial disfigurement and loss of swallowing and speech function make head and neck cancer patients suffer from unique and heavy physical and psychosocial burdens [18]; therefore, intensive holistic support is most important in this patient population.

A higher prevalence of breast cancer was identified in the nonelderly group compared with the elderly group in the present study. Leong et al. demonstrated that the peak age of breast cancer was lower (40–50 years old) in Asians, and this was quite different from the peak age in Western countries [19]. Grabsch et al. pointed out that women with advanced breast cancer had higher prevalence of psychological stress, which would affect quality of life [20]. Therefore, intensive physical and psychological care is necessary for women with advanced breast cancer [19–21].

Our results identified that nonelderly patients were more likely to suffer from insomnia, which was similar to the results in the literature [22], which suggested that physical discomfort, especially intractable pain, may disrupt sleep [23,24]. Psychosocial distress including anxiety and depression may also cause sleep problems [25]. Therefore, the higher prevalence of sleep disturbance in nonelderly advanced cancer patients may reflect more physical as well as psychosocial distress in nonelderly patients and this warrants further attention.

Our study revealed that nonelderly advanced cancer patients had a significantly higher percentage of emotional distresses than elderly patients. Ellis et al. reported similar results [26]. Walsh et al. also demonstrated that younger patients were associated with anxiety and depression [22]. Thompson et al. showed that younger advanced cancer patients tended to experience nonacceptance of the prognosis and reported more frequently feelings of hopelessness, suffering, depression and anxiety [27]. This may explain the higher emotional distress seen in nonelderly cancer patients.

Empirical evidence suggested that a large proportion of cancer patients in Taiwan were unaware of their disease/prognosis as they were approaching death [28]. In the present study, the overall proportion of unawareness of disease/prognosis is 35.1%, with 24.6% and 44.1% in the nonelderly group and elderly groups, respectively. This finding is compatible with previous research in Taiwan, which indicated that nonelderly patients had a higher level of disease awareness than elderly patients prior to death [29]. Another study from Taiwan revealed that truth-telling problems occurred in nearly one-half (42.6%) of the elderly population (>65 years old) with advanced cancer in Taiwan [30]. In Taiwanese culture, older ill patients rely heavily on family caregivers. "Unawareness of disease" is taken to be the result of a "white lie" by which family members maintain patients' will to live on. However, the higher prevalence of disease unawareness may indicate higher rates of unfulfilled wishes and unprepared funerals in the elderly patients, which are necessarily based on prognosis disclosure. Cross-cultural difference regarding disclosure of cancer prognosis was evident in the literature [31]. Truth-telling or disease disclosure to the elderly cancer subjects constitutes an important issue in Taiwan's hospice care.

Spirituality is one of the most important parts of palliative care for advanced cancer patients [6,7]. The literature identified relationship, meaning identification, peace and faith as four major elements of spirituality in terminal patients [8,32–35]. Though some instruments have been developed to assess spirituality [6,36], few scales are suitable for the Asian population because of religious and cultural differences. Christianity and Catholicism account for only 13% of the religious belief in Taiwan's population [37]. Religious differences cause differences of "death view" and pre-dying adjustments between western and eastern populations. Our study indicated that the six-item questionnaire of spiritual concerns would be pertinent to evaluate spiritual well-being in Taiwan's population and suitable for employment in further research.

Our study found that unfulfilled wishes were significantly more prevalent in the elderly group. As we have discussed, unawareness of disease/prognosis was more prevalent in the elderly group. We conducted further correlation analysis between these two factors, and the results revealed that unfulfilled wishes and unawareness of disease/prognosis were significantly correlated (correlation coefficient 0.206, $p < 0.01$). Fulfilling wishes would indicate accomplishing a good death for advanced cancer patients. For instance, seeing children finishing an educational degree or getting married are two examples given in the literature [18]. Not to inform a senior patient with advanced cancer of disease/prognosis may result in higher rates of unfulfilled wishes because approaching death was not included in communication, let alone talking about the wishes before death.

Our study revealed that younger patients were concerned more by an "unwillingness to pass away because of concern for loved ones". There is limited reference to this in the literature. However, nonelderly patients with advanced cancer have more concerns for loved ones because they may care more about their surviving parents, spouses or small children [18]. This specific spiritual suffering might also be explained by Erikson's psychosocial stages in the life cycle. In his theory, people who are more than 20 years old should primarily establish "intimacy" and those who are 40–60 years old should take "generativity" as their major task [38].

There are strengths and limitations in the present study. A retrospective study design which restricted the clarification of the causal relationship is one limitation. Though this is a single-center study, a large sample size with a good power is its strength. Another strength is that our data were collected by palliative care professionals and licensed hospice nurses, which increases the reliability of the investigation.

In conclusion, nonelderly patients with advanced cancer suffered from more physical, psychosocial and spiritual distress, including baseline pain level, breakthrough pain, insomnia, emotional distress, and unwillingness to pass away because of concern for loved ones. On the contrary, elderly cancer patients have a higher prevalence of prognosis unawareness and having unfulfilled wishes. There is much room for improvement on this condition. Intensive support for these vulnerable patients is therefore important in palliative care, especially in Taiwan's advanced cancer patients.

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