Cancer patient autonomy and quality of dying–a prospective nationwide survey in Taiwan

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Abstract

Background: Patient autonomy is an essential factor in the measurement of quality of dying. We aimed to conduct a study to investigate the factors affecting the autonomy of advanced cancer patients in Taiwan.

Methods: We conducted a prospective, multicenter study and recruited 574 advanced cancer patients from four inpatient hospice wards in Taiwan; their quality of dying was measured using the validated good death scale and the audit scale. Physician-assessed autonomy and the other scales were measured in a team conference by the primary care physician and the team 1 week after the patient had passed away. The good death scale was measured twice, once at admission and then after the patient had passed away for comparison. We measured factors affecting the improvement in quality of dying of these patients initially by applying multiple linear regression analysis. Then, taking physician-assessed autonomy as a dependent variable, we identified the factors that affected this variable.

Results: The good death score at admission, clear consciousness, number of admission days beyond 7, better physical care, higher physician-assessed autonomy, better emotional support, better communication, better continuity of life, and physician-reported rate of closure were factors affecting the quality of dying. Further analysis identified age ($p = 0.031$), consciousness ($p = 0.01$), and total good death scale score at death ($p < 0.001$) as determinants of physician-assessed autonomy.

Conclusions: We concluded that physician-assessed autonomy would affect a good death and was highly correlated with age, consciousness level, and quality of dying at the end for advanced cancer patients in Taiwan.
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Background

Despite the differences in the context of a good death, patient autonomy is sometimes regarded as one of the top domains in various cultures and religions [1–6] and is an essential component of the measurement tools for quality of dying [7,8]. From a policy perspective, the advocacy of advanced care planning is actually an honoring of patient autonomy [9,10]. However, it is generally agreed that the autonomy of only a very small proportion of dying patients can be fully honored, especially in Asia. Because most East Asian countries are under the influence of Confucianism and filial piety, patient autonomy is usually subordinate to family values [11–14].

In a literature review, it was apparent that most reports focus merely on the importance of patient autonomy in end-of-life discussions [15,16]. A study on home care among Dutch primary care physicians found loss of autonomy was one of the most unbearable sufferings of the terminally ill. Another qualitative study investigated the autonomy issue among advanced cancer patients in the USA and concluded that regardless of the ethnicity, most patients agree with the American value and think autonomy is paramount. Maintaining a sense of control is a core component of a dignified death. Nevertheless, few have further explored the issue as to the extent of patient autonomy and the factors affecting patient autonomy in advanced cancer patients.

Cancer has been the leading cause of death in Taiwan since 1982. More than 40,000 patients die of cancer each year, and the number is increasing. With advances in medical technology, both Taiwan and the West have followed a similar path, leading to improved palliative medicine and hospice care. The hospice movement started in 1983, and the first hospice was set up in 1990 at Mackay Memorial Hospital, a Christian-based hospital in Northern Taiwan. Many hospices were set up thereafter, mainly in private hospitals owned or sponsored by religious institutions. In 1995, National Taiwan University Hospital launched the first public ward devoted to providing palliative and hospice care, and aiming to integrate service with teaching and research and increase public awareness of palliative care. Taiwan's National Health Insurance reimburses all expenditures for palliative care, including inpatient care, home care, and team consultations. Taiwan is one of the first countries in Asia to certify palliative care specialists. A palliative care specialist training program was incorporated into the residency training of family medicine practitioners, who were certified after the fourth year (fellowship) of family medicine training. Now, there are around 600 palliative care specialists in Taiwan. Most of the Taiwanese people believe in traditional religion.

Our study group has been particularly interested in investigating the good death in the past years [4,17–19]. We designed the good death scale (GDS) and the audit scale (AS) as our outcome measures, and using these scales, we have published many articles on the quality of dying and pointed out the importance of patient autonomy in a series of studies [18,19] conducted in a single inpatient palliative care unit in Taiwan. We found that not only is patient autonomy low in the geriatric population but also that in a 10-year study, patient autonomy affected the quality of dying of advanced cancer patients.

We therefore aimed to conduct a multicenter, prospective study to investigate factors affecting the physician-assessed autonomy of advanced cancer patients. We hypothesized that physician-assessed autonomy would affect the good death of terminally ill cancer patients in Taiwan and that many factors would significantly correlate with the physician-assessed autonomy of dying patients.

Patients and methods

Setting

Our study patients were diagnosed with various terminal cancers, were admitted to the Hospice Palliative Care Unit in one of four hospitals all across Taiwan (National Taiwan University Hospital, China Medical University Hospital, National Taiwan University Hospital Yun-Lin Branch, and Kaohsiung Medical University Hospital) during the period August 1, 2011 through January 31,

2012, and met the criteria of the study. The institutional review board of each site approved the protocol.

Study sample

Because the study subjects were advanced cancer patients, we included only those that were in the hospice wards. The inclusion criteria were as follows:

1. stage IV malignancy refractory to available chemotherapy or any other curative treatment as determined by the original attending physician;
2. physical symptoms requiring hospitalization, or great psychological, social, or spiritual distress; and
3. consent provided by the patient or family member to accept palliative care services, and a signed living will or 'do not resuscitate' order.

The exclusion criterion was as follows:

1. Expiration within 24 h of admission to the hospice ward. If the patient passed away within 24 h of admission, we could not compare the quality of dying and measure the autonomy of the patient.

The criteria met by the primary care physician are as follows:

1. Responsibility for the patient's hospice care upon admission to the hospice.
2. Basic training in palliative care for at least 4 h, as certified by the hospital. Our intent was to improve the validity of the questionnaire by enrolling only those physicians familiar with the basic concepts and principles of palliative care.

Data collection

For each deceased patient in the hospice palliative ward, the primary care physician and the team completed a 'quality-of-dying' evaluation form. The form had three parts: Part one comprised basic patient data including name, chart number, room number, sex, day of death, age, primary site of cancer, religion, education, level of consciousness, main caregiver, and days of hospitalization. Part two was the 'GDS' and part three the 'AS.' The patient's level of consciousness was rated based on the response of the patient. If the patient was alert and fully responding to the question, consciousness was rated 'clear'. If the patient looked sleepy but still could be aroused, and responded to the question, consciousness was rated 'drowsy'. If the patient was not clear and seemed to have some auditory or visual hallucinations, we rated the patient's consciousness 'delirious'. If the patient was totally unconscious and not responding to any of the questions, we rated the patients 'comatose'.

The good death score was evaluated twice in a team conference: the first was upon admission for more than 1 day, to serve as a baseline, and the second was upon death at a usual weekly 'good death' team meeting. The team was made up of the primary care resident physician and attending physician, head nurse, main care nurse, social worker, volunteer, chaplains, and study researcher. The primary care physician and the team completed the AS, including the patient autonomy questionnaire after the GDS questionnaire, but only after the patient's death. A monthly teleconference was conducted, including the main researcher of each site, to discuss the obstacles or problems encountered during the data collection.

Measurements

Two instruments were used in the study: the GDS and the AS. The outcome (i.e., 'physician-assessed autonomy') was indicated by adding the scores of the autonomy categories (level of autonomy and medical decision-making participation) in the AS.

1. The GDS

Derived from a modified Weisman's definition of a good death and the opinions of experienced professionals in palliative care [20], the assessment of a good death in this study had five domains: awareness that one is dying (0 = complete ignorance, 3 = complete awareness), acceptance of death peacefully (0 = complete unacceptance, 3 = complete acceptance), honoring of the patient's wishes (0 = no reference to the patient's wishes, 1 = following the family's wishes alone, 2 = following the patient's wishes alone, and 3 = following the wishes of the patient and the family), death timing (0 = no preparation, 1 = the family alone had prepared, 2 = the patient alone had prepared, and 3 = both the patient and the family had prepared), and the degree of physical comfort 3 days before death (0 = a lot of suffering, 1 = suffering, 2 = a little suffering, and 3 = no suffering).

2. The AS for good death services

The AS measures the process of patient care. The original scale was classified into six domains (each with two items). Each item was appraised on a scale of 1 = 'extremely poor' to 5 = 'extremely good.' The six domains and 12 items were as follows: (1) physical care—symptom control and satisfaction of the patient and the family; (2) physician-assessed autonomy—level of autonomy and medical decision-making participation; (3) emotional support—alleviation of anxiety and resolution of depression; (4) communication—verbal support and nonverbal support; (5) continuity of life—continuity of social support and affirmation of one's past life; and (6) physician-

reported rate of closure—fulfillment of last wish and bereavement support.

The reliability and validity of the GDS in Taiwanese palliative care units have been well discussed in detail [18,19], and the instruments have been used and their results published in many journals [17–19,21–23]. Cronbach's α was used to assess the internal consistency of this good death measure in the present study and was found to be 0.71 for the five domains. A panel of two physicians, two nurses, one psychologist, two chaplains, and one social worker initially tested the entire instrument for content validity. All members of the panel were experts in palliative medicine. A content validity index was used to determine the validity of the structured questionnaire and yielded a score of 0.93. In addition, 10 volunteers (bereaved family members) filled out the questionnaire to confirm the questionnaire's face validity and ease of application.

For the AS, we used exploratory factor analysis to test construct validity. Bartlett's test of sphericity and the Kaiser–Meyer–Olkin test were used to confirm that the measure was appropriate for exploratory factor analysis (Bartlett's test of sphericity = 3373.56, Kaiser–Meyer–Olkin value = 0.871, $p < 0.01$). The draft items were analyzed using principal component factor analysis followed by orthogonal varimax rotation. The number of principal components to be extracted was determined by examining the eigenvalues (>1) and Cattell's scree test. The cutoff point of factor loading in the study was set at 0.5. Finally, the number of domains was reduced to two and named 'patient care' and 'social wellbeing'. Internal consistency was demonstrated, with the Cronbach's α coefficient ranging from 0.84 to 0.91 for the factors and 0.93 for total items of this measure. These two factors accounted for 65.4% of the total variance of the variables.

Statistical analysis

SPSS software (ver.11, Chicago, IL, USA) was used for data management and analysis. A two-sided p-value ≤ 0.05 was considered statistically significant. The categorical variable data are presented as frequency (proportion) and the continuous variable data as mean (standard deviation). The associations among the categorical variables were analyzed by chi-square test or Fisher's exact test, but continuous variables were compared between posttest and pretest in the same group using a paired t-test or Wilcoxon rank-sum test. Means and standard deviations of the 'good death' scores were compared, and a paired t-test was used to examine the change in the GDS scores on admission and after death. We conducted linear regression twice. First, in order to see the factors affecting the improvement in the GDS score of our patients, we defined the change in GDS score as our dependent variable. Linear regression analysis was conducted to identify the factors

associating with a mean change in GDS score. We did a change-score analysis, that is, $\Delta Y = Y_1 - Y_0$ was the outcome variable of our multiple linear regression model, so that the good death score at admission (i.e., Y_0) was added into the regression model as a control variable. All the univariate significant and nonsignificant relevant covariates (independent variables) were put on the variable list to be selected; they included sex, age, diagnosis, days of hospitalization, level of consciousness, religion, education, main caregiver, GDS at admission, and categories in the AS such as physical comfort, physician-assessed autonomy, composure, communication, continuity, and physician-reported rate of closure. Second, taking physician-assessed autonomy as the dependent variable, we ran another regression analysis with sex, age, diagnosis, days of hospitalization, level of consciousness, religion, education, main caregiver, change in GDS, GDS at admission, GDS at death, change in awareness, acceptance, propriety, timeliness, and comfort as the independent variables. The significance levels for entry and for retention or stay were set at 0.15 or greater. Then, based on clinical knowledge, the best final regression model was identified manually by reducing the significance levels to 0.05, corresponding to the chosen α level.

Results

Patient characteristics

Of the 621 patients admitted to the four sites from August 1, 2011 to January 31, 2012, 574 met the criteria of the study; 47 patients were excluded because they died within 24 h of admission. No physician was excluded. Most of the patients were from National Taiwan University Hospital (40.9%), and 51.6% were younger than 65 years old. Male patients were predominant (59.2%). A majority of patients were admitted for 8–30 days (50.7%). The top three primary tumor sites, in descending order of frequency, were gastrointestinal (23.9%), hepatobiliary (18.3), and respiratory (16.2%). The average number of days of admission was 13.5. Most of the patients were traditional in religion belief (40.2%), had received an elementary education (27.4%), had a clear consciousness level (49.1%), and were cared for by sons and daughters (44.4%) (Table 1).

Good death scale

All five domains of the GDS were improved after palliative care in the hospice ($p < 0.001$), and the mean increase in total score was 3.32 on a scale of 15 (Table 2).

The audit scale

In the distribution of AS scores, most domains were rated 'good' or 'extremely good' (Table 3)

Table 1. Patient demographics and clinical characteristics

Variable	N	%
Hospital		
National Taiwan University Hospital	235	40.9
National Taiwan University Hospital Yun-Lin Branch	48	8.4
China Medical University Hospital	142	24.7
Kaohsiung Medical University Hospital	149	26.0
Total	574	100.0
Age (years)		
<65	296	51.6
65	278	48.4
Sex		
Male	340	59.2
Female	234	40.8
Days of admission (days) (13.50 ± 14.74)		
1–7	241	42.0
8–30	291	50.7
>31	42	7.3
Primary sites of tumor		
Gastrointestinal	137	23.9
Hepatobiliary	105	18.3
Respiratory	93	16.2
Head and neck	76	13.2
Gynecological	35	6.1
Breast	30	5.2
Pancreas	27	4.7
Unknown	10	1.7
Others	61	10.7
Religion		
None	62	10.8
Traditional	231	40.2
Taoist	62	10.8
Buddhist	161	28.0
Christian/Catholic	29	5.1
Others	27	4.6
Education		
Illiterate	68	11.8
Elementary	157	27.4
Junior high	98	17.1
Senior high	135	23.5
College/postgraduate	90	15.7
Others	26	4.5
Main caregiver		
Wife	159	27.7
Husband	59	10.3
Children	255	44.4
Parents	30	5.2
Sibling	33	5.7
Others	38	6.7
Consciousness		
Clear	282	49.1
Drowsy	148	25.8
Delirious	76	13.2
Comatose	65	11.3
Others	3	0.5

Associations with improvement in good death scores

Univariate analysis showed that gynecological ($p = 0.02$) and head and neck ($p = 0.048$) tumors, consciousness (clear versus others, $p < 0.001$), religion (yes versus none, $p = 0.019$), admission days > 7 ($p < 0.001$), total GDS

Table 2. Differences in various domains of good death score between admission and prior to death

Domains	At admission (mean)	At death (mean)	Difference (mean)	t	p
Awareness	1.77 ± 0.80	2.53 ± 0.68	0.74 ± 0.71	24.588	<0.001
Acceptance	1.97 ± 0.64	2.53 ± 0.65	0.56 ± 0.63	20.935	<0.001
Propriety	2.23 ± 0.96	2.65 ± 0.76	0.42 ± 0.77	12.990	<0.001
Timeliness	1.97 ± 1.03	2.72 ± 0.66	0.75 ± 0.94	19.064	<0.001
Comfort	1.91 ± 0.63	2.79 ± 0.42	0.88 ± 0.64	30.290	<0.001
Total score	9.89 ± 2.91	13.25 ± 2.23	3.32 ± 2.39	32.673	<0.001

score at admission, higher physical care score on the AS ($p < 0.001$), higher physician-assessed autonomy scores on the AS ($p < 0.001$), better emotional support score on the AS ($p < 0.001$), better communication score on the AS ($p < 0.001$), and better continuity of life and physician-reported rate of closure score on the AS were significantly related to a higher GDS score. Aside from the total GDS score at admission (which was negatively related), multivariate analysis identified clear consciousness ($p < 0.001$), number of admission days more than 7 ($p = 0.003$), better physical care ($p < 0.001$), higher physician-assessed autonomy ($p = 0.018$), better emotional support ($p = 0.006$), better communication ($p = 0.046$), better continuity of life ($p = 0.003$), and physician-reported rate of closure ($p < 0.001$) as factors affecting improvement in good death scores. Any discrepancy between the results of univariate analysis and multivariate analysis was likely caused by the confounding effects of the uncontrolled covariates in the univariate analysis.

Associations with physician-assessed autonomy

Aside from age, univariate analysis showed that consciousness ($p < 0.001$), education ($p = 0.018$), admission

days >14 ($p = 0.032$), difference in GDS ($p < 0.001$), and total score and all scores on GDS items at admission except comfort ($p < 0.001$), total GDS score at death and on all items ($p < 0.001$), difference in acceptance ($p < 0.001$), difference in propriety ($p = 0.005$), and difference in comfort ($p < 0.001$) (Table 4) were significantly related to a higher physician-assessed autonomy score. Aside from age (which was negatively related), multivariate analysis identified consciousness ($p = 0.01$) and total GDS score at death ($p < 0.001$) as associations affecting physician-assessed autonomy.

Discussion

To our knowledge, this is the first nationwide study focusing specifically on determinants of physician-assessed autonomy in advanced cancer patients.

It is not surprising to learn that autonomy status declines as the patient ages. Our previous study pointed out that elderly persons in Taiwan usually are not aware of the terminal status of their illness, which further jeopardizes their autonomy [18]. For years, there has been a tendency to not disclose the illness to the elderly patient out of fear of the consequent psychological trauma. However, as studies have reported that awareness of the disease is actually beneficial to patient autonomy and quality of dying [18,24,25], educational programs for medical students and attending physicians concerning communication and 'truth-telling' have been initiated nationwide during the past several years. A compassion training program has been included in the formal curriculum of medical students. For residents and attending physicians, this training is carried out in the form of case-based workshops sponsored by the Taiwan Academy of Hospice Palliative Medicine [26,27]. All

Table 3. Audit scale results at death of patients admitted to four hospices

Categories of audit scale	Extremely poor 1	Poor 2	Fair 3	Good 4	Extremely good 5
Physical care					
Symptom control	0	9(1.6%)	59(10.3%)	269(46.9%)	235(40.9%)
Patient and family satisfaction	1(0.2%)	7(1.2%)	61(10.6%)	239(41.6%)	264(46.0%)
Physician-assessed autonomy					
Level of autonomy	1(0.2%)	12(2.1%)	71(12.4%)	206(35.9%)	274(47.7%)
Medical decision-making participation	0	11(1.9%)	53(9.2%)	219(38.2%)	281(49.0%)
Emotional support					
Alleviation of anxiety	1(0.2%)	4(0.7%)	85(14.8%)	238(41.5%)	228(39.7%)
Resolution of depression	1(0.2%)	7(1.2%)	90(15.7%)	231(40.2%)	227(39.5%)
Communication					
Verbal support	0	4(0.7%)	31(5.4%)	173(30.1%)	357(62.2%)
Nonverbal support	0	4(0.7%)	30(5.2%)	158(27.5%)	378(65.9%)
Continuity of life					
Continuity of social support	1(0.2%)	12(2.1%)	75(13.1%)	176(30.7%)	308(57.3%)
Affirmation of one's past life	2(0.3%)	10(1.7%)	120(20.9%)	207(36.1%)	218(38.0%)
Physician-reported rate of closure					
Fulfillment of last wish	3(0.5%)	14(2.4%)	112(19.5%)	198(34.5%)	230(40.1%)
Bereavement support	0	5(0.9%)	50(8.7%)	210(36.6%)	307(53.5%)

Table 4. Associations of patient autonomy of advanced cancer patients from four hospices in Taiwan

Variables	Univariate analysis			Multivariate analysis		
	Beta	95% CI	*p*-value	Beta	95% CI	*p*-value
Intercept						
Sex (male)	0.057	−0.064, 0.349	0.177			
Age ≧65	−0.111	−0.564, −0.083	0.009	−0.091	−0.512, −0.024	0.031*
Primary site of malignancy						
Gastrointestinal	0.037	−0.158, 0.408	0.386			
Respiratory	−0.025	−0.429, 0.229	0.551			
Hepatobiliary	−0.028	−0.417, 0.209	0.514			
Breast	0.023	−0.406, 0.709	0.593			
Pancreas	0.067	−0.110, 1.022	0.114			
Gynecological	0.037	−0.280, 0.724	0.385			
Head and neck	0.027	−0.240, 0.469	0.526			
Musculoskeletal	0.038	−1.552, 4.202	0.366			
Unknown	−0.030	−1.316, 0.617	0.478			
Hematological	−0.070	−2.376, 0.202	0.098			
Other	−0.083	−0.828, −0.001	0.050			
Main caregiver						
Spouse versus others	0.078	−0.016, 0.487	0.066	0.015	−0.192, 0.281	0.711
Consciousness						
Clear versus others	0.164	0.239, 0.718	<0.001	0.102	0.071, 0.529	0.010*
Religion						
Yes versus no	−0.071	−0.735, 0.061	0.097	−0.022	−0.459, 0.252	0.567
Education						
Above senior high versus junior high	0.101	0.052, 0.555	0.018	0.044	−0.107, 0.372	0.276
Day of admission						
>7 days versus <7 days	0.080	−0.008, 0.482	0.058	−0.015	−0.278, 0.188	0.704
>14 days versus <14 days	0.090	0.024, 0.526	0.032			
Difference in good death scale	0.149	0.041, 0.142	<0.001			
Good death scale at admission	0.248	0.085, 0.167	<0.001	−0.045	−0.072, 0.026	0.351
Awareness	0.314	0.432, 0.723	<0.001			
Acceptance	0.259	0.412, 0.784	<0.001			
Propriety	0.165	0.128, 0.380	<0.001			
Timeliness	0.171	0.127, 0.361	<0.001			
Comfort	−0.046	−0.297, 0.086	0.281			
Good death scale at death	0.497	0.280, 0.376	<0.001	0.508	0.272, 0.396	<0.001***
Awareness	0.452	0.825, 1.149	<0.001			
Acceptance	0.399	0.732, 1.078	<0.001			
Propriety	0.323	0.477, 0.783	<0.001			
Timeliness	0.255	0.399, 0.764	<0.001			
Comfort	0.281	0.694, 1.241	<0.001			
Difference in awareness	0.070	−0.026, 0.316	0.097			
Difference in acceptance	0.149	0.156, 0.541	<0.001			
Difference in propriety	0.117	0.068, 0.387	0.005			
Difference in timeliness	−0.009	−0.144, 0.116	0.834			
Difference in comfort	0.213	0.277, 0.619	<0.001			

*$p < 0.05$,
**$p < 0.01$,
***$p < 0.001$.

these efforts are designed to enhance the communication skills of physicians and further ensure the autonomy of advanced cancer patients.

Consciousness level was also significantly related to physician-assessed autonomy. The clearer the patient, the better the patient can make decisions for himself or herself or become involved in advanced care planning. The latter is especially important for patients at the end stage of life because he or she can decide to reduce futile treatment without too much suffering. The patient may discuss with the attending physician the appropriate use of fluid and nutrition, nasal gastric tubes, blood transfusions, antibiotics, or even terminal sedation. In our study, nearly half of the patients were consciously clear at the end, and we found these patients were more actively involved in the preparation of a good death.

Physician-assessed autonomy was very much related to the GDS score at death. Our study indicated that the

greater the patient autonomy, the higher the score would be. The achievement of quality of dying is mainly attributed to the efforts of the palliative care team members. Every essential component of the GDS score is actually a continuous process and aimed at honoring autonomy. When the medical staff discloses the bad news to the patient and helps the patient accept it, the patient is then able to make many medical decisions (awareness and acceptance), and the medical plan can be initiated according to the patient's will. The patient can also make arrangements and fulfill his wishes (propriety). The appropriate timing of death will also depend upon the patient's choice of treatment (timeliness). Finally, the physical suffering of the patient can be greatly alleviated as the result of choosing comforting care (comfort).

This study is subject to several limitations. First of all, because of the nature of the study, it was evaluated by proxy attending staff in the inpatient ward. Second, it is difficult to define autonomy when the patient's consciousness is impaired during admission. Third, the study was limited to inpatients only, and those receiving home care or in nursing homes were not included. However, the results are concordant with previous related studies [18,19].

Conclusion

We conclude that physician-assessed autonomy will affect the good death and is highly correlated with age, consciousness level, and quality of dying at the end in advanced cancer patients in Taiwan.

Acknowledgements

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