

An exploratory investigation into advance care planning, end-of-life communication and decision-making in an acute hospital setting

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Abstract

Objective: To examine advance care planning (ACP), end-of-life (EoL) communication and decision-making in an acute hospital setting for future practice and service development.

Design: A mixed method approach involving a chart audit, a self-administered survey, and focus group interviews was adopted. Setting: Data were collected at the Alice Ho Miu Ling Nethersole Hospital (AHNH) in Hong Kong between January 2016 and September 2016.

Participants: 61 patients who died within 180 days from death in 2014-2015 were selected for a chart audit. 107 healthcare workers attending EoL workshops completed the survey. Two focus group interviews with 6 patients and 7 family members were formed separately.

Measurements: Patients' records including ACP and EoL conversation engagement, completion of advance directives (AD), and use of life-sustaining treatments and special procedures were audited. A 16-item self-competence in death work scale (SC-DWS) was self-administered by health care workers. A semi-structured interview guide covered questions on EoL communication, preferences for information and decision-making was discussed among patients and family members.

Findings: Documented evidence of engaging ACP (0%), EoL conversation (21%), completion of AD (0%), do-not-attempt cardiopulmonary resuscitation (DNACPR) orders (79%) were noted. 41 out of 61 patients (67.2%) underwent special procedures with about 1-5% of patients experienced invasive procedures and 18 patients undertook life-sustaining treatments (29.5%). The total SC-DWS score was 60.14 (SD= 8.16, range: 16 to 80) with existential subscale score of 38.06 (SD=5.165, range: 10-50) and emotional subscale score of 14.20 (SD=2.593, range: 4 to 20). Most of the patients had conversation with health care workers, but the content mainly on their health conditions with no opportunity to discuss their preferences for treatment and care related to EoL. Both patients and family members wanted to be informed about the patient's health condition. Most patients favored physician-centered decision-making, while family members favored shared decision-making. Keywords: advance care planning; end-of-life communication; decision-making

Introduction

Hong Kong was ranked 22 in a list of 80 countries featured in the 2015 Quality of Death Index.¹ In the palliative and healthcare environment category of the index, Hong Kong ranked 28 with a relatively low ranking position compared to other low-income and middle-income countries such as Mongolia (ranked 24) and Panama (ranked 25). The index highlights the significant deficiencies in the provision of high-quality EoL care in Hong Kong.

In this study, a mixed method approach was adopted to examine advance care planning (ACP), end-of-life (EoL) communication and decision-making in an acute hospital setting.

A retrospective chart review for patients who died within 180 days from death was used to identify gaps in the current EoL practices at an acute hospital setting. A survey and focus group interviews were employed to understand healthcare workers' self-competence in coping with death work and explore preferences of patients and family members for medical information and decision-making. These triangular information altogether can guide us to formulate better plans for service development and the continual improvement of the quality of EoL care at the public hospitals.

Methods

A mixed method approach involving a chart audit, a self-administered survey, and focus group interviews was adopted.

Chart audit

The chart audit data were reviewed from patient medical records and discharge summaries at the AHNH. Patients' records including ACP and EoL conversation engagement, completion of advance directives (AD), and use of life-sustaining treatments and special procedures were audited.

Survey on healthcare workers' self-competence in death work and their opinions

The self-administered survey included a validated self-competence in death work scale (SC-DWS)² and an open-ended question. Healthcare workers at the AHNH were asked to complete the survey following the EoL workshops. The SC-DWS were used to assess their levels of self-competence in coping with death work. Two aspects of self-competence were measured: the existential subscale score assessed the challenges related to life and death perspective and meaning in life, and the emotional subscale score assessed the challenges related to emotions such as grief and sense of helplessness.

A total of 17 questions were asked including 16-items SC-DWS and 1 open-ended question. The items were summed to yield a total score that ranged from 16 to 80, with a higher score indicating greater self-competence in death work. The open-ended question on the opinions towards death work was included following the 16-items SC-DWS.

Focus groups about patient/family views on EoL care

Focus group interviews with patients and family members were conducted separately at the AHNH. A semi-structured interview guide was developed to cover questions on EoL communication, preference for information, and decision-making. Interviews were audio-taped, transcribed and analyzed by thematic content analysis.

Results

Rate of ACP and EoL communication

A total of 61 patients who died within 180 days from death between November 2014 and April 2015 were selected for review and the description for study participants is shown in Table 1. The median age at death was 90 years for females and 82 years for males. None of the patients (0%) signed AD nor had ACP documented during their 180 days before death (Table 1). 48 patients (79%) signed DNACPR form and 13 patients (21%) had engaged in EoL conversation.

Figure 1. indicates that 41 patients (67.2%) had undergone at least one special procedures during admissions in their 180 days before death. Among them, about 1-5% of patients experienced invasive procedures (i.e., lung drainage or biopsy: 3 patients (4.9%); paracentesis: 3 patients (4.9%); mechanical ventilation: 2 patients (3.3%); upper gastrointestinal endoscopy : 2 patients (3.3%); and bone marrow examination: 1 patient (1.6%)). 18 patients (30%) received tube-feeding while 6 patients (10%) received BiPAP and 7 patients (11.5%) had applied CPR.

Self competence in death work

A total of 107 surveys were collected from the AHNH's healthcare workers between January 2016 and September 2016. The demographics of study participants and their scores in SC-DWS are shown in Table 2.

The total SC-DWS was found to be varied significantly by age, years of work experience and the number of end-of-life training previously received. Older participants and having more than 20 years of work experience had higher scores in the total SC-DWS (p<.001). Also, participants who had received end-of-life care training showed greater self-competence than those who had no training(p<.001). 21 out of 107 participants answered the open-ended question with 19 nurses, 1 doctor and 1 occupational therapist. Some opinions are shown in Box 1.

Patient and family views on EoL care

Views from 6 patients and 7 family members were collected from focus group interviews at the AHNH in September. Patients would like to know more about their health conditions. Most family members pointed out a lack of communication on EoL topics with patients and healthcare professionals and they wanted to be informed about the patients' health conditions. Most patients favored physician-centered decision-making, while family members expressed that they would compromise with other family members and doctors for decision-making on the basis of patients' choices. Box 1 lists some of the patients' and family members' responses.

Table 1. Description of study participants from the chart audit

Variables (N=61)	N	%
Female	36	59.02%
Admitted from old age home	33	54.10%
Place of death - medical ward	61	100.00%
Referred to specialist palliative care	2	3.28%
Bed-bound	16	26.20%
Chair-bound	22	36.00%
Bed-bound and chair-bound	4	6.56%
Chronic health problems*	61	100.00%

	Mean	Median	S.D.
Age at death (both females and males)	84.7	88	12.10
Age at death (females)	87.97	90	10.17
Age at death (males)	79.88	82	12.97
Average length of hospital stays during their last 180 days	21.34	11	30.23
Average length of death in their last admission	11.18	4	24.10

Note. * chronic health problems include cancer, heart problem, hypertension, hyperlipidemia, pneumonia, chronic obstructive pulmonary disease, gastric ulcer, renal problem, arthritis, stroke, parkinson disease, dementia and diabetes mellitus.

Completion of ACP, AD, DNACPR and EoL conversation	N	%
ACP	0	0.00%
AD	0	0.00%
DNACPR	48	78.69%
EoL conversation	13	21.31%

Figure 1. Use of life-sustaining treatments and special procedures

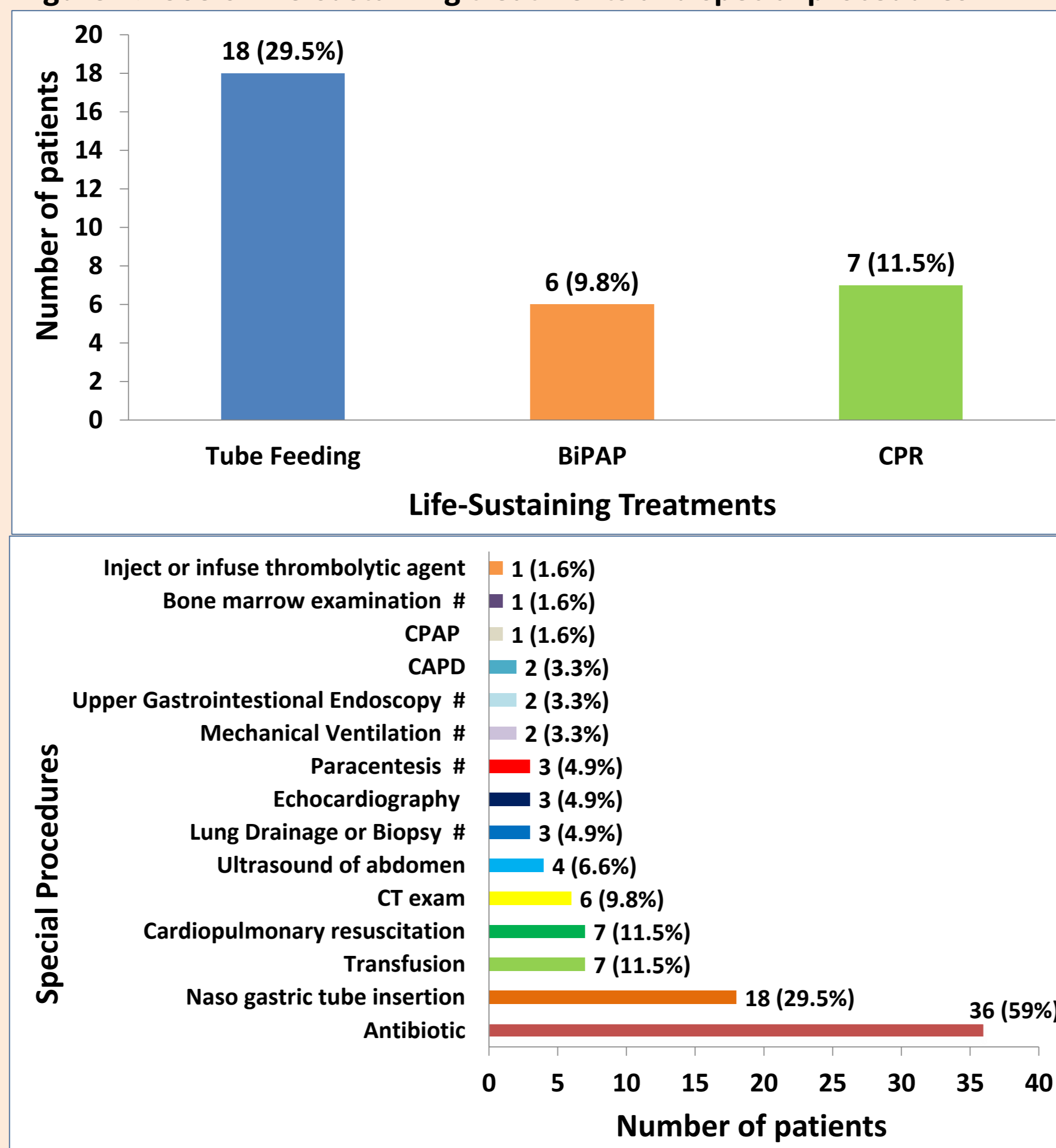


Table 2. Demographics and scores of the SC-DWS among healthcare workers at the AHNH

	N	%	Total SC-DWS	p-value	Existential subscale score	p-value	Emotional subscale score	p-value
Gender								
Female	84	79.2%	60.79		38.42		14.40	
Male	22	20.8%	57.77		36.59		13.65	
Total	106	100%	60.16	0.172	38.05	0.171	14.24	0.278
Age group								
18-29	30	28.6%	56.87		35.93		13.43	
30-39	19	18.1%	56.79		35.55		13.63	
40-49	36	34.3%	61.50		39.47		14.27	
50 and above	20	19.0%	66.35		41.40		16.10	
Total	105	100.0%	60.25	0.001	38.09	0.000	14.26	0.009
Years of work experience								
<1	5	4.7%	56.80		36.40		12.80	
1-5	25	23.6%	57.00		35.88		13.64	
6-10	10	9.4%	57.20		35.80		13.30	
11-15	8	7.5%	58.00		36.56		14.13	
16-20	25	23.6%	59.36		37.68		13.92	
21-25	10	9.4%	67.20		43.50		15.36	
26-30	16	15.1%	62.50		39.69		14.87	
>30	7	6.6%	68.00		41.86		16.86	
Total	106	100%	60.16	0.001	38.05	0.001	14.24	0.031
Occupation								
Doctor	9	8.5%	62.22		39.56		14.33	
Nurse	91	85.8%	60.03		38.01		14.18	
Others	6	5.7%	59.00		36.33		15.00	
Total	106	100%	60.16	0.748	38.05	0.587	14.24	0.735
Department								
Medicine	66	64.7%	59.82		37.79		14.20	
Surgery	6	5.9%	62.00		39.14		13.83	
Others	30	29.4%	60.67		38.37		14.52	
Total	102	100%	60.20	0.748	38.05	0.762	14.27	0.712
Number of End-of-life care training received in the past year								
0	21	50.0%	54.29		34.77		12.19	
>1	21	50.0%	62.76		39.71		14.95	
Total	42	100%	58.52	0.005	37.19	0.006	13.6	0.005

Box 1: Responses from healthcare workers, patients and family members

Healthcare workers' opinions towards death work

"Staff require a rotation plan to avoid long-term negative emotional impacts induced by keep working at a ward (that patients would die) or a palliative ward for a long time." (Doctors, MED, Female, Age 50-59, No religion)

"How to release "end of life" as popular correction to minimize sorrow/bereavement." (Nurse, Psychiatric, Female, Age 50-59, No religion)

Patients' and family members' responses on EoL communication and decision-making

Patient group

Patient medical decision-making

"I would listen to the doctor's advice. I would accept resuscitation if the doctor thinks it can save my life. If the doctor points out I am terminally ill, I would listen to him and don't postpone my death." (Male, Age 75-79, No religion)

"The family members don't have knowledge on medical treatment, the decision depends on the doctor." (Male, Age >80, No religion)

Family group

Communication with healthcare workers

"The doctor would tell the medical information briefly if you don't raise out questions. If their attitudes are more positive and friendly, patients and family members would be more positive. Healthcare professionals require counseling in a certain extent to make their mind more open and positive." (Female, Age 50-54, No religion)

"When talking about end-of-life care, it is the communication between doctor and family members. No compromise reaches without communication, nothing can be done." (Female, Age 60-64, Taoism)

Patient medical decision-making

"When the patient is awaked, the medical decision should be made by patient. When he is not, doctor and family members make the decision." (Female, Age 50-54, No religion)

"Why don't we respect the patient's choice on treatment? If the patient had made the decision, the family members should reach a compromise. Family may suffer for a period of time but it is a peaceful death for the patient." (Female, Age 60-64, Taoism)

Conclusion

No documentation of ACP or AD was found during the audit period and the EoL conversations were primarily focused on the completion of DNACPR order. This may be a reflection of inadequate documentation practice or a lack of patient and practitioner knowledge and awareness of ACP. The survey on SC-DWS further demonstrated that provision of training sessions on EoL care for young and less-experienced healthcare workers would be more likely to increase self-competence in death work. Findings of focus group interviews highlighted that most of the patients had conversations with health care workers, but the content were discussed mainly on health conditions with no opportunity to discuss their preferences for treatment and care related to EoL. Both patients and family members wanted to be informed about the patient's health condition and majority of family members showed respect to patient medical choice. Most patients favored physician-centered decision-making, while family members favored shared decision-making. It is therefore important to engage patients, family members and practitioners having ACP discussions to maximize the congruence between patient and family member's preferences. Efforts should be made to strengthen practitioners' skills in performing ACP discussions so that an informed patient's decision with all complex medical decisions that patients may face, not only decision about the particular medical procedures, such as CPR, can be made.

References

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