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Going home to die from surgical intensive care units

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S.-J. Huang Department of Surgery, National Taiwan University Hospital Yun-Lin Branch, Yun-Lin, Taiwan

W.-J. Ko Department of Traumatology, National Taiwan University Hospital, 7 Chung-Shan S. Road, Taipei, Taiwan Abstract Purpose: To better understand events related to going home to die (GHTD) from the intensive care unit (ICU), with the hope that this information might improve the palliative care of ICU patients. Methods: This retrospective observational study was performed at a tertiary medical center—the National Taiwan University Hospital. All surgical ICU mortality cases between 1 January 2003 and 31 December 2007 were included in this study. Results: The rate of GHTD from the ICU declined annually, but has reached a plateau of around 25% in recent years. Multivariate logistic regression analysis found independently significant factors associated with GHTD, including older age (OR: 1.013; P = 0.001), married status (OR: 2.128; P < 0.001), lower educational level (OR: 1.799; P = 0.001), and lack of DNR consent

(OR: 1.499; P = 0.006). When treatment intensity was compared on the date of death, GHTD patients in general received more treatments and diagnostic procedures than those who died in the ICU. Univariate analysis showed that GHTD patients received significantly more advanced antibiotics, more chest radiography, greater use of sedatives, greater use of analgesics, and more transfusions, but less FiO₂ and mechanical circulatory support than patients who died in the ICU. Conclusion: GHTD from the ICU is a special phenomenon in the Chinese cultural area, representing a cultural tradition rather than a form of palliative care.

Keywords Mortality · Surgical intensive care unit · Place of death · End-of-life care

Introduction

Many patients with advanced, incurable cancer would prefer to spend their final days at home, where they may have more control over their environment, more autonomy and privacy, and a greater sense of normalcy than they would have in a hospital setting [1-3]. In study of Tang [4], nearly 90% of the terminal cancer patients preferred to die at home, and they acknowledged dying at their preferred place of death as highly important. Although a review of the literature showed many publications on the phenomenon of "going home to die"

among terminally ill cancer patients, only few reports were found on leaving the intensive care unit (ICU) to die at home [5-9]. In these reports, there were only few patients, ranging from 1 to 17 patients. This might be that patients in the ICU usually receive more aggressive treatment than non-ICU patients and are less likely to be labeled as terminal or needing palliative care. This is especially true in the surgical setting, where major operations are part of a great effort to sustain life and reverse critical illness. In our surgical ICU, however, we found that it was not uncommon for terminal patients to go home to die. This study was conducted to examine the prevalence of going home to die (GHTD) from our surgical ICU and investigated the differences between those who went home to die and those who died in the ICU (DICU). Our aim was to better understand events related to GHTD from the ICU, with the hope that this information might improve the palliative care of ICU patients.

Methods

This retrospective observational study was performed at National Taiwan University Hospital (NTUH), a 2,000-bed tertiary medical center with a full range of departments. One-third of organ transplant procedures in Taiwan are performed at NTUH, which has a well-known extracorporeal membrane oxygenation (ECMO) program. The hospital is located in the center of Taipei, a metropolitan city in northern Taiwan with a dense population of 4 million, and treats critical-care patients referred from throughout the Taipei metropolitan area. Taiwan belongs to the so-called Chinese cultural circle. About 98% of the island's people are of Han Chinese ethnicity.

Data collection

The surgical ICU at NTUH comprises five units: the 20bed cardiovascular surgery (CVS) ICU, the 8-bed chest surgery (CS) ICU, the 11-bed neurosurgery (NS) ICU, the 16-bed general surgery (GS) ICU, and the 9-bed trauma ICU. In January 2003, the surgical ICU began maintaining records of all patients who ultimately died, for quality-assurance purposes. Data collected included the following: (1) patient characteristics: age, sex, religion, education, occupation, marital status, consciousness level at ICU admission, type of operation (elective or emergent), ICU admission diagnosis, and cause of death; (2) ICU course data: date of ICU admission, date of do-notresuscitate (DNR) consent, date of death or ICU discharge, and length of ICU stay; (3) treatment intensity: FiO₂, ventilator use, antibiotic use, chest radiography, blood sampling for laboratory examination, inotropic equivalent (IE) [10, 11], dialysis, mechanical circulatory support (MCS), nutrition, transfusion, sedative use, analgesic use, and neuromuscular blocking agent (NMBA) use at time of ICU admission, DNR signature, and death. All the patients in the surgical ICU between January 2003 and December 2007 who ultimately died were included in this study.

Mortality patients

The mortality patients included those who died in the ICU and those who died at home after being discharged from

the ICU at the terminal stage. When the patient's clinical status became irreversible, the attendant physician would discuss with the families about end-of-life care. They will discuss about DNR, organ/tissue donation, or taking the patient home. If the family chose to take patient home, we would inform them when the patient's life nearly came to an end (usually when the patient's systolic blood pressure was <80 mmHg even under inotropes infusion), so that the patient could be taken home to die.

Usually, our terminal patients had been under dormicum and morphine infusion for sedation. If not yet done, we would add the drugs to the IV drip along with the patient when going home. The patient was kept intubated with ventilator support to maintain "breathing" and with vasopressive drugs to maintain the blood pressure during transport. A nurse usually accompanied the patient home with family members. Upon arriving, the patient was gently placed on a bed in the main hall, and the nurse withdrew the endotracheal tube and vasopressive drugs, but preserved the sedatives and analgesics until the patient was asystole, with family members staying at the bedside during the process. Death would ensue within minutes to hours.

Statistical analysis

Statistical analysis was performed using SPSS software, version 11.5. Normally or near-normally distributed variables are reported as mean \pm standard deviation (SD). Means were compared using one-way analysis of variance (ANOVA). Categorical data were assessed using the Chi-square test or Fisher's exact test.

Results

Numbers of surgical ICU admissions, numbers of deaths, and GHTD rates among patients who died are shown for each year of the study, from 2003 to 2007, in Table 1. The GHTD rate declined annually before reaching a plateau of around 25% in recent years. The numbers of GHTD and DICU patients for each age group is shown in Fig. 1.

The characteristics of GHTD and DICU patients are compared in Table 2. Univariate analysis revealed that GHTD patients were older than DICU patients and had higher rates of unemployment, religious faith, and married status, a lower educational level, and a lower rate of DNR consent. A statistically significant difference between the two groups was also found in the distribution of surgical sections (CVS, CS, NS, GS, and others). All of the variables shown in Table 2 except surgical sections were entered into the multivariate logistic regression model: the continuous variable of age; the binary variables of gender, occupation, religion, and marital status;

Table 1 Yearly trend (2003–2007) of admission number, mortality number, and number of patients going home to die in the terminal stage in SICU patients of NTUH

Year	2003	2004	2005	2006	2007
ICU admission	2,620	3,755	4,192	4,131	4,132
ICU mortality ^a	145 (5.5)	200 (5.3)	296 (7.1)	232 (5.6)	276 (6.7)
Go home to die from ICU ^b	64 (44.1)	77 (38.5)	81 (27.4)	56 (24.1)	68 (24.6)

NTUH National Taiwan University Hospital, SICU surgical intensive care unit

^a Data are presented as mortality number (% of ICU admission)

die among our SICU patients were significantly different (P < 0.001 by Chi-square test)

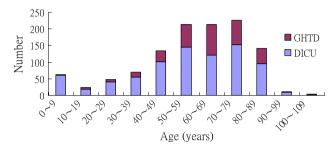


Fig. 1 The number of patients who go home to die from ICU (*GHTD*) or die in the ICU (*DICU*) in each age group

and level of education. Multivariate logistic regression analysis found independent significant factors associated with GHTD, including older age (OR: 1.013; P=0.001), married status (OR: 2.128; P<0.001), lower educational level (OR: 1.799; P<0.001), and lack of DNR consent (OR: 1.499; P=0.006). The GHTD rates in the CVS, CS, NS, GS, and "other" sections were 22.6, 37.2, 21.2, 37.3, and 31.8%, respectively.

When GHTD patients were taken home, their mean systolic and diastolic blood pressures were 71.6 ± 34.7 and 40.0 ± 18.1 mmHg, respectively, and mean heart rate was 97.0 ± 31.3 . Thus, the patients were discharged only when death was imminent. Comparison of treatment intensity between GHTD patients on the date of ICU discharge and DICU patients on the date of ICU death is shown in Table 3. In general, GHTD patients received more treatments and diagnostic procedures than DICU patients on the date of death. Univariate analysis showed that GHTD patients received significantly more advanced antibiotics, more chest radiography, greater use of sedatives, greater use of analgesics, and more transfusion; however, they received significantly less FiO₂ and MCS.

Discussion

Before the widespread availability of acute-care hospital facilities, most deaths occurred at home. Home death rates have declined markedly over the past century [12], averaging approximately 20% for all deaths in the 1990s in

Table 2 Comparison of characteristics between patients who go home to die from ICU (GHTD) or die at ICU (DICU)

	GHTD $n = 346$	$ DICU \\ n = 803 $	P value
Age (years)	62.6 ± 16.2	55.0 ± 23.5	< 0.001
Sex (male)	227 (65.3)	524 (65.6)	0.482
Occupation			0.029
Yes	129 (37.3)	349 (43.5)	
No	217 (62.7)	454 (56.5)	
Religion			0.006
Yes	251 (72.5)	520 (64.8)	
No	95 (27.5)	283 (35.2)	
Marital status ^a			< 0.001
Married	281 (81.2)	526 (65.5)	
Unmarried	65 (18.8)	277 (34.5)	
Education level	, ,		< 0.001
Nil	70 (20.2)	118 (14.7)	
Elementary/junior high school	194 (56.1)	319 (39.7)	
Senior high school	49 (14.2)	179 (22.3)	
University/graduate	33 (9.5)	187 (23.3)	
Section			< 0.001
CVS	74 (21.4)	253 (31.5)	
CS	45 (13.0)	76 (9.5)	
NS	41 (11.8)	152 (11.8)	
GS	165 (47.7)	277 (34.5)	
Others ^b	21 (6.1)	45 (5.6)	
DNR	230 (66.5)	579 (72.1)	0.033

Data are presented as number (%) of patients or mean \pm standard deviation

CS Chest surgery, CVS cardiovascular surgery, DICU die in the ICU, DNR do not resuscitate, GHTD go home to die, GS general surgery, NS neurosurgery

^a Married included married and cohabitated; unmarried included unmarried, divorced, widowed, and separated

^b "Others" section includes departments of plastic surgery, orthopedic surgery, otolaryngology, obstetrics and gynecology, and urology

developed countries [13]. The past 30 years, however, have seen the development of hospices and palliative care teams and units focused on improving end-of-life care and encouraging people to determine where they wish to die, if possible. Most terminally ill people prefer to die at home rather than in the hospital. This has led to a recent increase in the home death rate in some countries. In the United States, the percentage of home deaths nationally increased

^b Data are presented as number of patients going home to die from ICU (% of mortality cases). Yearly percentages of going home to

Table 3 Comparison of treatment intensity between GHTD patients on the date of ICU discharge and DICU patients on the date of ICU mortality

	GHTD $n = 346$	DICU $n = 803$	P value
Length of ICU stay ^a	13.6 ± 21.6 (7) 324 (93.6)	15.0 ± 29.4 (7)	0.423
Ventilator		744 (92.7)	0.321
FiO ₂ Antibiotics ^b	0.61 ± 0.25	0.65 ± 0.27	0.017 0.037
Nil	65 (18.8)	212 (26.4)	
1°	21 (6.1)	37 (4.6)	
2°	103 (29.8)	231 (28.8)	
3°	157 (45.4)	323 (40.2)	
IE ^c	22.2 ± 42.6	24.3 ± 43.1	0.470 0.432
Dialysis ^d	95 (27.5)	215 (26.8)	
Lab	231 (66.8)	498 (62.0)	0.071
CXR	179 (51.7)	371 (46.2)	0.049
Sedative	140 (40.5)	242 (30.1)	<0.001
Analgesic NMBA	173 (50.0) 47 (13.6)	295 (36.7) 127 (15.8)	<0.001 <0.001 0.190
MCS ^e Nutrition ^f	33 (9.5)	126 (15.7)	0.003
	135 (39.0)	280 (34.9)	0.101
Transfusion	137 (39.6)	273 (34.0)	0.040

Data are presented as number (%) of patients or mean \pm standard deviation (median)

CXR Chest X-ray, DICU die in the ICU, DNR do not resuscitate, FiO_2 fraction of inspired oxygen, GHTD go home to die, IE inotropic equivalent, Lab blood sampling for laboratory examination, MCS mechanical circulatory support, NMBA neuromuscular blocking agent

- ^a Presented as mean \pm standard deviation (median)
- b Nil, No antibiotic use; 1° includes ampicillin, oxacillin, penicillin G, benzathine penicillin G, penicillin V, dicloxacillin, amoxicillin, first generation cephalosporines, gentamicin, neomycin, streptomycin, clindamycin, metronidazole, erythromycin, pipemidic acid, chloramphenicol, doxycycline, minocycline, tetracycline; 2° includes amoxicillin + clavulanate, ampicillin + sulbactam, second generation cephalosporines, tobramycin; 3° includes ticarcillin + clavulanate, piperacillin + tazobactam, third generation cephalosporines, amikacin, isepamicin, aztreonam, imipenem + cilastatin, meropenem, ertapenem, ciprofloxacin, levofloxacin, moxifloxacin, norfloxacin, colistin, vancomycin, teicoplanin, linezolid
- c $\stackrel{\text{L}}{\text{IE}} = [(\text{dopamine} + \text{dobutamine}) + (\text{milrinone} \times 15) + (\text{epinephrine} + \text{norepinephrine} + \text{isoproterenol}) \times 100]$ in mcg/kg/min [10, 11]
- ^d Dialysis includes continuous veno-venous hemofiltration, hemodialysis, or peritoneal dialysis
- ^e MCS included extra-corporeal membrane oxygenation or intraaortic balloon pump
- f Nutrition included naso-gastric tube feeding and total parental nutrition

from 16 to 23% from the late 1980s to 2001. The rate varied considerably from state to state, ranging from a low of 12.4% in Washington, DC, to a high of 38.4% in Oregon [14]. In some countries, however, including Italy and Japan, a trend toward hospital deaths persisted [15, 16].

For chronically terminally ill patients such as those with advanced cancer, home death rates are higher. Between 1997 and 2003, the percentage of cancer deaths occurring at home in Taiwan was at least 60% [17] and as

high as 69%, according to Tang [18]. This rate is higher than those found for other countries, such as the UK (22% in 2003) [19], the US (29–35% in 1994–1998) [19, 20], and Canada (26.3% in 1992–1997) [21].

Dying at home has a special cultural meaning for Chinese patients and their families. Dying in the main hall of one's own house is known by the Chinese as "dying peacefully in one's bed." This is considered to be the most glorious and fortunate manner of death [22]. Thus, "the fallen leaves can return to their roots." When death occurs at home, the spirit of the deceased can reunite with the forebears and will not be a "koo'un'ia' kui" (spirit wanderer), a solitary soul with no one on whom to depend. These cultural factors could explain the higher home death rate found in terminally ill patients in Taiwan.

The literature reveals that it is common for terminalstage cancer patients to die at home. For intensive care patients, however, for whom the primary goal is to treat and cure, going home to die is rare. Many invasive lifesupportive treatments and monitors on patients also prevent ICU patients from going home to die at the terminal stage. Only few studies were found regarding going home to die from the ICU. Beuks et al. [5] described two such cases in the Netherlands. Mann et al. [8] and Ryder-Lewis et al. [9] reported on 17 patients (over a 7-year period) and 14 patients (over a 4-year period), respectively, who were taken home from the ICU to be with their families in their last hours in New Zealand. Boussarsar et al. [6] and Kallel et al. [7] also reported their experiences respectively in Tunisia. Among surgical ICU patients at NTUH, however, going home to die at the terminal stage is not uncommon, with rates ranging from 44.1 to 24.6% during the study period of 2003–2007. Apparently, the traditional belief that people should die at home motivated relatives to take patients home from cure-oriented institutions like the ICU when death was imminent.

Many studies have been conducted on factors that influence place of death in terminally ill patients with cancer. We found that older age, lower education level, married status and lack of DNR consent were significantly associated with going home to die from the ICU. Many other studies also reported that older patients were more likely to die at home [14, 17, 23–26]. These findings are in accord with the value placed on dying at home in the Chinese tradition. In contrast to our study, however, Howat et al. [27] found that younger patients were more likely to die at home. They explained that younger patients usually have younger and fitter spouses, along with willing friends and relatives, to aid in their care. In our ICU, however, patients were always taken home by their children. Thus, older age was not a negative factor in going home to die in our study. Lower educational level was also reported to be related to dying at home in other studies [24, 26]. Patients with lower educational levels usually lived in areas characterized by lower socioeconomic levels, where the patients could die at home more conveniently than in modern urban areas. After the patient died, the family usually held a funeral at home. Many studies also found married status to be associated with dying at home [17, 19, 27, 28]. Possible reasons for this finding include that married patients are more likely to have a committed caregiver (the spouse) to provide end-of-life care at home. Paradoxically, the DNR rate of GHTD patients seemed to be significantly lower than that of DICU patients. This meant that GHTD and DNR were not equivalent end-of-life care in our surgical ICU.

Although having religion was not significantly associated with GHTD in our study, we believed that religion and ethnicity had an impact on the patients' choices of the places of their death. Two of the five exsisting GHTD studies are about Islamic countries [6, 7]. Muslims have a specific conception of death, and the vast majority of them desire to die at home, in their own bed, and to experience some cultural and religious rituals while surrounded by their family and friends [7]. In another study of Mann et al. [8], all 17 patients were Maori or Polynesian. The Chinese tradition also favors people choosing to go home to die at the terminal stage of illness.

However, in our surgical ICU, GHTD patients were not like terminal cancer patients and ICU patients in other countries, for whom going home to die might occur when patients' conditions were still stable. Our patients were taken home only at their terminal stage, when their blood pressure was very low. At that time, their treatment intensity was even higher than that of DICU patients at the time of death except for MCS and FiO₂. It may be that patients with MCS were not allowed to go home to die.

The significantly greater use of analgesics and sedatives in GHTD patients may have been due to the desire to make the patients, as well as family members, more comfortable during transport.

Limitations of the study

There were some limitations in our study. First, the generalization was limited because our results were derived from the experience of SICU in a single center, and all of our patients were of Chinese ethnicity. Second, this is a retrospective study. We need further prospective study to understand why the GHTD rates decrease over time and more details about things happening in the patients' homes.

Conclusion

Going home to die is satisfying to both patients and their families because it allows families to be together at home at the time of death, a situation that is culturally favored in the Chinese tradition. In Taiwan, however, going home to die from the ICU was not like the situation in other countries, which marked the transition to palliative care. Treatment was still intense when the patients were taken home to die. Thus, going home to die from the ICU is a special phenomenon in the Chinese cultural circle, representing a cultural tradition rather than a form of palliative care.

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