

# The do-not-resuscitate order for terminal cancer patients in mainland China

## A retrospective study

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### Abstract

With the development of palliative care, a signed do-not-resuscitate (DNR) order has become increasingly popular worldwide. However, there is no legal guarantee of a signed DNR order for patients with cancer in mainland China. This study aimed to estimate the status of DNR order signing before patient death in the cancer center of a large tertiary affiliated teaching hospital in western China. Patient demographics and disease-related characteristics were also analyzed.

This was a retrospective chart analysis. We screened all charts from a large-scale tertiary teaching hospital in China for patients who died of cancer from January 2010 to February 2015. Analysis included a total of 365 records. The details of DNR order forms, patient demographics, and disease-related characteristics were recorded.

The DNR order signing rate was 80%. Only 2 patients signed the DNR order themselves, while the majority of DNR orders were signed by patients' surrogates. The median time for signing the DNR order was 1 day before the patients' death. Most DNR decisions were made within the last 3 days before death. The time at which DNR orders were signed was related to disease severity and the rate of disease progression.

Our findings indicate that signing a DNR order for patients with terminal cancer has become common in mainland China in recent years. Decisions about a DNR order are usually made by patients' surrogates when patients are severely ill. Palliative care in mainland China still needs to be improved.

**Abbreviations:** AD = advance directive, CPR = cardiopulmonary resuscitation, DNR = do-not-resuscitate, EOL = end-of-life, HIS = hospital information system, HPCA = Hospice Palliative Care Act, NCICF = notice of critical illness claim form.

**Keywords:** do-not-resuscitate order, EOL decision making, palliative care, patients with cancer

## 1. Introduction

Aggressive treatment cannot prolong the survival time of most patients with end-stage cancer, but it can increase suffering and the family's burden,<sup>[1,2]</sup> posing a dilemma for physicians from ethical and legal standpoints.<sup>[3–6]</sup> Advance directive (AD) is a process of discussion and a formalized document with patients and their caregivers about their wishes for treatment and care

planning when they become unable to make medical decisions because of illness or incapacity.<sup>[7]</sup> A do-not-resuscitate (DNR) order, which is a written medical directive that indicates refusal of cardiopulmonary resuscitation (CPR) following sudden cardiac or respiratory arrest,<sup>[8]</sup> is thought to be an important part of terminal patients' AD.<sup>[9]</sup> A DNR order is regarded as valuable in helping patients to be treated with dignity in their last days,<sup>[9–12]</sup> and increasingly more patients with terminal cancer choose to sign DNR orders.<sup>[13]</sup>

By signing a DNR order, a patient refuses artificial life support that would delay death; this is currently a widespread practice in many countries.<sup>[14–16]</sup> A DNR order can also be written to avoid futile treatment and resuscitation while continuing appropriate symptom-attenuated treatment.<sup>[17,18]</sup> The "right to die" was first discussed in an American study by Rabkin et al<sup>[19]</sup> in 1976. New York was the first state to approve DNR orders in 1988.<sup>[20]</sup> In Europe, DNR orders are routinely utilized in cases where providing CPR to a patient would be futile.<sup>[15,21]</sup>

Although Japan has no official guidelines for DNR orders,<sup>[22]</sup> it was the first Asian country to address "death with dignity" as "an act of withdrawing or withholding all life-prolonging measures on the basis of patients' wishes when they are in their terminal stage of life."<sup>[23,24]</sup> In China, Taiwan has a similar definition.<sup>[3]</sup> On June 7, 2000, the Hospice Palliative Care Act (HPCA) was signed into law in Taiwan, allowing a natural death for terminal patients, including DNR orders. In Taiwan and other Asian countries, most DNR orders are signed by patients' relatives; less than 20% are signed by patients themselves.<sup>[25–27]</sup> In Hong Kong, DNR orders can only be signed by physicians after evaluating the patient's best interest.<sup>[28]</sup>

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Currently, the rate of DNR orders signed for terminal patients in Hong Kong is 94.7%.<sup>[16]</sup>

The first person who advocated “death with dignity” and “advance directive” in mainland China was Ms. Diandian Luo, who founded the public welfare website, “Choice and Dignity.” Patients can register on the website and fill in their treatment-relevant choices, based on “five wishes”: Whether I need this medical service, Whether I wish to use life support, How I wish to be treated by others, What I wish my family and friends knew, and Who I wish to offer help to me. On June 25, 2013, Ms. Luo formally established the Beijing Living Will Promotion Association (Beijing Living Will Promotion Association (2015). Choice and Dignity, <http://www.xzyzy.com>. Accessed July 29, 2016.)

In mainland China, there is no formal legislation about AD. In clinical practice, if there is a risk of cardiac or respiratory attack, physicians will inform patients’ families of the poor prognosis. Patients’ surrogates are then asked to sign their consent to indicate whether the patient accepts invasive treatment, such as endotracheal intubation. If they refuse invasive treatment, this could be regarded as a DNR order.<sup>[29]</sup>

Currently, most literature on DNR orders of Chinese cancer patients is from Hong Kong and Taiwan. This introduces bias when estimating palliative care for Chinese ethnic populations. Our study was performed in the cancer center of a large-scale affiliated teaching hospital in mainland China. We investigated the use of DNR orders and influencing factors such as patient demographics and disease-related characteristics for patients with terminal cancer who died in the hospital between January 2010 and February 2015.

## 2. Methods

### 2.1. Study design and population

This was a retrospective study of all patients diagnosed with solid tumors who died in the cancer center of a large affiliated teaching hospital in western China from January 2010 to February 2015. Electronic records were reviewed by specialized data managers and research assistants.

Inclusion criteria were patients with a pathologically confirmed cancer diagnosis who died in the oncology ward. Exclusion criteria were patients with early-stage cancer who died from noncancer-related causes and patients who were <14 years old at death.

### 2.2. Data collection

Access to patients’ data was approved by the director of the oncology department, and our study was approved by the hospital’s institutional review board. The medical records of all patients hospitalized in the cancer center from January 2010 to February 2015 were collected and the last records before death were reviewed manually. A consent for CPR refusal, including chest compression, endotracheal intubation, or assisted mechanical ventilation, was regarded as a DNR order. The person who signed the DNR order was confirmed by examining medical records. Demographic information, disease-related information, and information related to the Notice of Critical Illness Claim Form (NCICF) were also collected. In mainland China, a NCICF is equivalent to an informed consent with the signature of both a physician and a patient’s surrogate. A signed NCICF indicates that the patient is critically ill, and death might occur at any time.

The variables to be collected were determined by literature review.<sup>[14,27]</sup> Demographic information included age, sex, and marital status. Disease-related information included cancer type

and NCICF status. Both types of information were extracted from the hospital information system (HIS) and input into an excel form by a specialist from the hospital’s information department. Patient or surrogate signature, signature date, and surrogate-patient relationship were included with the signed DNR order. Receiving a NCICF occurs when a patient is critically ill and any aggressive treatment such as CPR could not prolong the survival time.<sup>[1,2]</sup> As a result, NCICF was chosen as a related variable to analyze the status of DNR order.

### 2.3. Statistical analysis

The signed DNR order information, demographic, and disease-related characteristics were analyzed using descriptive analyses. The Chi-squared test was used to investigate differences in demographics and cancer type between patients with or without DNR orders. Univariate and multivariate logistic regression analyses were used to examine associations between demographic, disease, and DNR order variables (such as the interval between signing the DNR order and time of death). Linear regression analysis was used to examine the associations of the intervals between the time of signing the DNR order and the time of death after first receipt of the NCICF. All reported *P* values are 2-tailed, and *P* < .05 was considered significant. Statistical analyses were performed using IBM SPSS version 19.0 (Armonk, NY: IBM Corp).

## 3. Results

### 3.1. Patient characteristics

Data from 365 patients who died in our oncology ward from January 2010 to February 2015 were analyzed. Patient characteristics are summarized in Table 1.

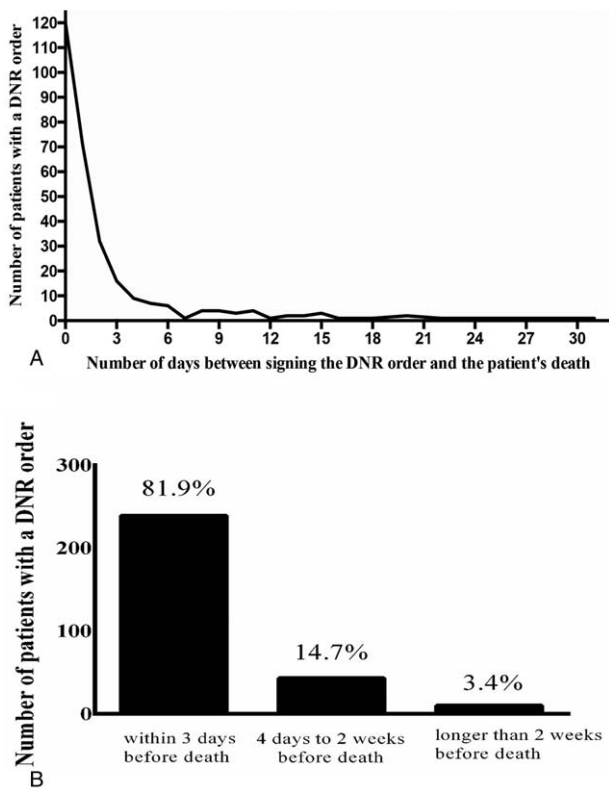
**Table 1**  
Demographic and disease-related characteristics among patients with or without DNR order.

	Entire population, n (%)	Signed DNR order	
		With, n (%)	Without, n (%)
Participants	365 (100)	292 (80)	73 (20)
Median age, y (range)	57 (14–88)		
<60 y of age	197 (54)	160 (81.2)	37 (18.8)
≥60 y of age	168 (46)	132 (78.6)	36 (21.4)
Sex			
Male	233 (63.8)	182 (78.1)	51 (21.9)
Female	132 (36.2)	110 (83.3)	22 (16.7)
Marital status			
Married	336 (92.0)	268 (79.8)	68 (20.2)
Unmarried*	29 (8.0)	24 (82.8)	5 (17.2)
Primary cancer			
Lung	151 (41.4)	119 (78.8)	32 (21.2)
Digestive tract†	117 (32.1)	93 (79.5)	24 (20.5)
Other types	97 (26.6)	80 (82.5)	17 (17.5)
Breast cancer	20 (5.5)	–	–
Gynecological	17 (4.7)	–	–
Urogenital	8 (2.2)	–	–
Head and neck	13 (3.6)	–	–
Lymphoma	21 (5.8)	–	–
Melanoma	2 (0.5)	–	–
Sarcoma	6 (1.6)	–	–
Primary site unknown	10 (2.7)	–	–

DNR = do-not-resuscitate.

\* Includes single, divorced, and widowed.

† Includes gastric, colorectal, liver, pancreatic, esophageal, and biliary cancer.



**Figure 1.** The time interval between signing the DNR order and the patient's death (n=292). (A) In most situations, a DNR order was signed near the patient's death. The earlier before the day of death, the less DNR orders were signed. (B) The majority of DNR orders (239/292,81.7%) were signed within 3 days of the patient's death; 43 (14.7%) were signed 4 days to 2 weeks before the patient's death; only 10 (3.4%) were signed 2 weeks or more before the patient's death. DNR = do-not-resuscitate.

**3.2. DNR order signing rates**

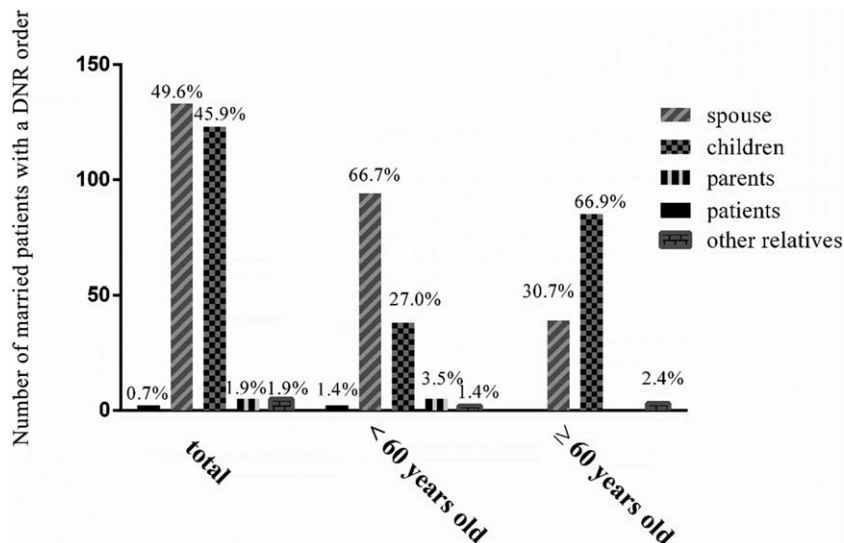
Among the investigated cases, 80% (292/365) had a signed DNR order before death. The time intervals between signing the DNR order and patient death is shown in Fig. 1A. The median time for signing the DNR order was 1 day before death (range: 0–31 days), and the mean interval was  $2.38 \pm 4.27$  days. Who signed the DNR order was not significantly associated with patient sex, age, marital status, or cancer type (Table 1).

**3.3. The time of signing a DNR order**

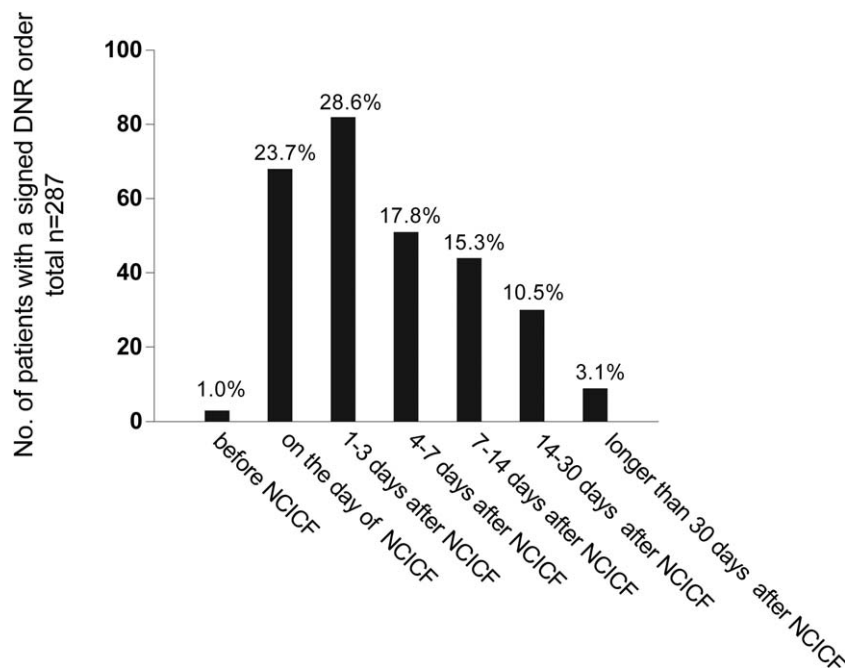
The majority of DNR orders (239/292, 81.9%) were signed within 3 days of patient death, while 120 (41.1%) patients had a DNR order signed on the day of death. Patients with lung cancer were more likely than patients with other cancers to have a DNR order earlier than 3 days before death [odds ratio, 2.198; 95% confidence interval (95% CI), 1.203–4.018;  $P = .01$ ]. Consent to a DNR order within 3 days before death was not affected by patient age, sex, or marital status (Fig. 1B).

**3.4. The person who signed the DNR order**

Of all the cases we studied, only 2 patients signed their DNR orders, whereas patient surrogates signed the majority of the DNR orders. In all cases of patient surrogates, the DNR order was authorized beforehand by the patient. Primary patient surrogates were spouses (135, 46.2%) and children (131, 44.9%). Among the married group (268/292, 91.8%), patients who were >60 years old (127/268, 47.4%) were more likely to have a DNR order signed by their children (85/127, 66.9%), while patients <60 years old (141/268, 52.6%) were more likely to have a DNR order signed by their spouse (94/141, 66.7%) (Fig. 2).



**Figure 2.** The person who signed the DNR order by age group among married patients (n=268). Only 2 patients signed the DNR order themselves; 133 (49.6%) DNR orders were signed by the patients' spouse, 123 (45.9%) were signed by the patients' adult children, and 5 (1.9%) were signed by the patient's parent or other relatives. Married patients <60 years old (141/268, 52.6%) were more likely to have a DNR order signed by their spouse (94/141,66.7%) than by their children (38/141, 27.0%). Five and two DNR orders were signed by the patients' parents or other relatives, respectively. Married patients >60 years old (127/268, 47.4%) were more likely to have a DNR order signed by their children (85/127, 66.9%) than by their spouse (39/127,30.7%). The remaining 3 had DNR orders signed by other relatives.



**Figure 3.** The proportion of patients with a signed DNR order by interval of time between receiving the NCICF and signing the DNR order ( $n=287$ ). DNR=do-not-resuscitate; NCICF=Notice of Critical Illness Claim Form.

### 3.5. The timespan between receiving the NCICF and signing the DNR order

The majority of terminal patients (353/365, 96.7%) received a NCICF at least once during hospitalization. Among patients with a DNR order, 98.3% (287/292) had received 1 NCICF. Only 3 patients (1.0%) had a signed DNR order before they received the first NCICF. The median time was 3 days after receiving the NCICF (earliest, 10 days before receiving the NCICF; latest, 86 days after receiving the NCICF). Sixty-eight patients (23.7%) signed DNR orders on the day they received the first NCICF, and 70% (201/287) signed the DNR order within 1 week of receiving the first NCICF (Fig. 3). After receiving the first NCICF, faster disease progression was related to earlier DNR order signing. The 2 timespans were positively associated ( $R=0.925$ ;  $R^2=0.856$ ;  $P<.001$ ).

## 4. Discussion

Hospice care enforcement varies widely depending on cultural background and region.<sup>[6,8]</sup> In 2007, the rate of DNR order signing for patients with terminal cancer was 50% to 60% in European countries and 57% in Korea.<sup>[27]</sup> As an indicator of palliative care, DNR order is not a new topic in western countries. However, over the past decade, hospice and palliative medicine have only recently emerged as a focus in China.<sup>[30]</sup> In Taiwan, the rate of DNR order signing before and after the HPCA passed in June 2000 was 64.4% and 77%, respectively.<sup>[25,31]</sup> In our study, at least 1 DNR order was found in 80% of medical records (Table 1). This rate is similar to current rates in Japan, the USA, and Taiwan (76%, 86%, and 77%, respectively).<sup>[14,25,32]</sup> DNR orders were once thought to indicate abandoning life and waiting for death.<sup>[33]</sup> However, this view has changed dramatically in the last decade since the evolution of palliative care.<sup>[29,34,35]</sup> Several studies reported that when medical professionals educated patients with cancer about palliative treatment options, DNR

orders increased.<sup>[36,37]</sup> A study of African-Americans revealed that palliative care education for patients and their families increased DNR orders from 34% to 35.5% to 65%.<sup>[36]</sup> Another study showed that discussions between oncology physicians and patients or patient surrogates regarding end of life (EOL) care are associated with fewer patients receiving futile medical measures.<sup>[38–41]</sup> Therefore, palliative care education is likely to increase the DNR order signing rate.

In our study, only 0.7% of DNR orders were signed by patients (2/292). Most DNR orders were signed by patients' spouses (46.2%) or children (44.9%). Although this rate is similar to Korea (0%) and Singapore (6.2%),<sup>[26,27]</sup> other east Asian countries and regions have much higher rates than mainland China<sup>[25]</sup>; in Japan, 20% of patients made the decision,<sup>[14]</sup> and the rate in Taiwan is 17.9%.<sup>[25]</sup> Patient engagement in ADs, of which DNR orders are thought to be an important part,<sup>[9]</sup> is critical to the provision of quality EOL care, as it has been linked with patients' wishes being more likely to be known and followed by providers.<sup>[42,43]</sup> Furthermore, DNR orders given by patients are associated with higher quality of life.<sup>[44,45]</sup> Liang et al<sup>[46]</sup> found that for patients with advanced cancer, a DNR order signed by the patient indicates a more favorable quality of EOL care. As only 2 DNR orders in our study were signed by patients, this may indicate insufficient EOL palliative care and suboptimal doctor-patient communication.<sup>[32,47]</sup>

Although mainland China and Taiwan stem from the same ancestors and culture, they are influenced by different sociopolitical factors.<sup>[48]</sup> Taiwan was once a Japanese colony and typically follows American practices, while mainland China's reform and opening-up policy occurred less than 40 years ago. These historic-cultural differences have led to different attitudes and practices in EOL care between mainland China and Taiwan.<sup>[49]</sup> In our study, most patients with cancer were over 40 years old (320/365, 87.6%) and nearly half of the married patients with a DNR order were over 60 years old (127/268,



47.4%). This group is usually heavily influenced by traditional Chinese Confucian culture (“familism” and “filial piety”), and appointed their adult children to make important decisions when they are severely ill,<sup>[50,51]</sup> which is in accordance with our result shown in Fig. 2.

From a historical perspective, Japan and Korea were both in the “Chinese culture circle.”<sup>[52]</sup> These 3 countries have interacted culturally and historically for centuries.<sup>[53]</sup> However, EOL issues are shaped by the integrated effect of culture, socioeconomic development, health care system, and so on.<sup>[54]</sup> It is hard to ascribe the differences in DNR order signing to a single cause. Although Japan is an Asian country culturally and geographically, from the politico-economic viewpoint, it is often thought to be a “western country” and has a relatively better national health care system compared with Korea and China, which may partially explain the difference.<sup>[53,54]</sup>

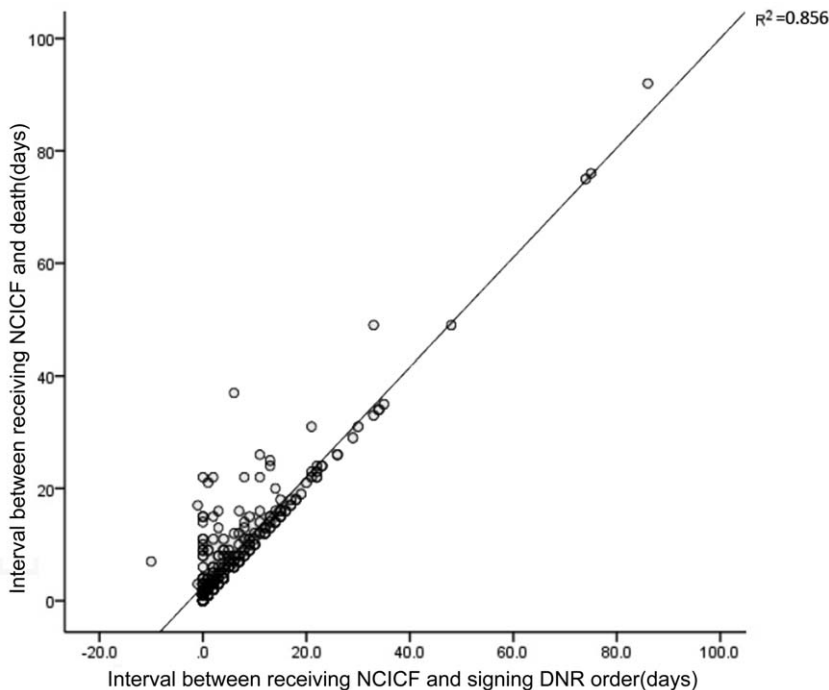
Nearly half of western patients with cancer sign their own DNR orders.<sup>[32]</sup> In western countries, such as the United States and the United Kingdom, decisions related to hospice care are made on account of patient autonomy and best interest.<sup>[55,56]</sup> In Muslim countries wherein jurisprudence remains distinct from elsewhere in the world, the decision of signing a DNR order is made by 3 physicians, without the involvement of the patient’s family or legal guardian.<sup>[57,58]</sup> In mainland China, many medical staff make decisions regarding life-sustaining treatment or DNR orders only after communication with patients’ surrogates.<sup>[59,60]</sup> Throughout the world, it appears that there is no standardization about DNR order.<sup>[8]</sup> Consensus on policy or law could improve attitudes regarding DNR orders and encourage clinicians to make medical decisions in favor of patients themselves.<sup>[61,62]</sup>

We found that signing DNR orders on the day of the patients’ death was most common (120/292, 41.1%). An increase of DNR order signing occurred as death approached (Fig. 1). The median

time was 1 day before death; 81.9% (239/292) were signed within 3 days of death (including the day of death), suggesting that most decisions to abandon futile invasive treatment were made when death is imminent. The earliest time for signing a DNR order was 31 days before death. A previous study showed that a short interval between DNR order and patient death indicates a need to improve doctor–patient communication regarding EOL goals of care.<sup>[32,47]</sup> Our study findings indicate a possible lack of doctor–patient communication in mainland China. In Taiwan, the time of signing a DNR order was 29 and 16 days before death, respectively, for patients informed or not informed of their real condition,<sup>[63]</sup> indicating that patients who understood their real condition might sign a DNR order earlier. In our previous study, although most patients with cancer in mainland China knew their cancer diagnosis, they were unclear on the real disease stage and prognosis.<sup>[64]</sup> As such, we hypothesize that patients were not fully informed of their disease condition, leading to the decreased timespan between signing the DNR order and death. This result suggests that concealment may delay DNR decisions, while full disclosure of disease condition could help reduce futile and painful treatment.

Cancer classification also influences the timing of signing a DNR order. Compared with other patients, patients with lung cancer were more likely to have a DNR order signed more than 3 days before death (25.2% vs 6.7%), suggesting that poorer somatic symptoms and prognosis make patients abandon treatment earlier.<sup>[65]</sup> In clinical practice, patients with lung cancer usually have a poor prognosis and higher performance status score, and medical staff would communicate with patients or their surrogates earlier.<sup>[29]</sup>

Nearly all families of patients with a DNR order (98.3%) received a NCICF before death. Only 3 patients had a DNR order before receiving a NCICF, and 23.7% were signed on the day of



**Figure 4.** The correlation between the time interval between signing the DNR order and receiving the NCICF and the interval between receiving NCICF and death. DNR = do-not-resuscitate, NCICF = Notice of Critical Illness Claim Form. \*Linear regression analysis revealed a close correlation between the time interval between receiving the NCICF and signing the DNR order and the interval between receiving the NCICF and death.  $y = 2.587 + 0.974x$ ;  $R = 0.925$ ;  $R^2 = 0.856$ ;  $P < .001$ .

receiving the NCICF (Fig. 3). This result suggests that most patients and their surrogates would not withdraw or withhold invasive treatment until disease progresses to a severe condition. In clinical practice, non-hospice care physicians usually communicate with patients' surrogates about EOL care when patients are severely ill.<sup>[66]</sup> These health providers have not been trained in professional EOL communication skills. From their perspective, discussing imminent death with patients or their families in advance is unpleasant.<sup>[65]</sup> Our research also showed a positive correlation between the interval of time between receiving the NCICF and signing a DNR order and the interval between receiving the NCICF and time of death (Fig. 4), suggesting that the timing of signing a DNR order is relevant to disease severity and progression.

On the basis of previous studies and the discussion above, we can infer that there are several obstacles to implementing palliative care service in mainland China: traditional Chinese Confucian culture lead to a misunderstanding of palliative care; policy problems and limited funding support from government for palliative care and research; and a deficiency of palliative care specialists.<sup>[51,67,68]</sup> Early notification of the disease condition and persistent education about palliative care for patients and their families could encourage the decision-making of patients with terminal cancer, and reduce futile medical interventions.<sup>[69,70]</sup>

Our research was retrospective; thus, patients' psychological states and the reasons for deciding for or against a DNR order cannot be known. Although studies from other countries have found that religion is an important factor influencing DNR orders,<sup>[6,61]</sup> medical records in China have no such information. It may be necessary to perform a prospective study about the impact of religion on DNR orders in China. In addition, because this was a single-center study, selective bias and errors could not be avoided. Our next step is to perform a multicenter study among general hospitals, hospice centers, and palliative wards.

To conclude, the rate of signing DNR orders in mainland China is similar to that in other Asian countries and regions. However, the proportion of DNR orders signed by patients themselves is much lower than that in Western countries or in other Asian countries, which could be due to differences of traditional culture, socioeconomic development, health policy, education, and so on. More efforts should be made to develop and implement palliative care in mainland China.

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