ORIGINAL ARTICLE

Is it feasible to discuss an advance directive with a Chinese patient with advanced malignancy? A prospective cohort study

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Objectives Advance directives have been implemented for years in western countries, but the concept is new to Asian cultures. According to traditional Chinese culture, family members usually play a decisive role in a patient's treatment plan. Thus it may be hard to implement an advance directive despite its importance to the treatment of patients. The objectives of this study were to assess the feasibility of advance directive engagement and to explore significant contributing factors to achieving such a goal.

Design Prospective cohort study.

Setting Palliative Care Unit of Clinical Oncology, Tuen Mun Hospital, Hong Kong.

Patients The subjects of the investigation were adult patients diagnosed to have advanced malignancy and newly referred to the hospice service from 24 April 2009 to 30 July 2009. Data were collected from nursing assessment forms, locally designed advance directive forms, a checklist completed by oncologists, and details available in the electronic hospital record.

Results Of the 191 eligible patients, 120 (63%) had the advance directive, whereas 71 (37%) did not. In the Cox regression model, the patient having insight of a poor prognosis was the most significant factor facilitating advance directive engagement (P=0.001). Any family objection in the discussion of advance directives was also an important factor, though it did not reach statistical significance (P=0.082). Other factors like age, gender, education, religion, financial status, living environment, understanding the diagnosis, bereavement experience, type of cancer, nature of illness, courses of chemotherapy or radiotherapy received, main caregiver, in-house supporter, nurse-led clinic attendance, clinical psychologist consultation, and in-patient hospice nurse coordinator interview were all statistically insignificant.

Conclusions Our study demonstrated that it was feasible to discuss an advance directive with Chinese patients with advanced malignancy. When patients have insight about their poor prognosis and family members have no objection, it may be appropriate to discuss an advance directive.

Key words
Advance care planning; Advance directives; Neoplasms; Patient self-determination act; Terminal care

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New knowledge added by this study

- This is a service model in Hong Kong showing that advance directive (AD) is not only conceptually possible, but also feasible in practice.
- Positive and negative factors influence AD engagement.

Implications for clinical practice or policy

- The discussion could be carried out by oncologists who can answer questions about the patient's health condition and AD engagement.
- Cooperation with other discipline can promote effective AD engagement.
- More credit for AD discussion in Hospital Authority hospitals can promote the concept in other units.

Introduction

Since the late 70s and early 80s, advance directive (AD) was brought up for discussion in the US and many western countries. However, even after years of promotion and legislation for The Patient Self-Determination Act launched in the US since 1990, the completion rate of the ADs in the population remains low (26%).[1]

In traditional Chinese culture, death was a very sensitive issue, and mentioning it was sacrilegious and to be avoided.[2] It was believed to be disrespectful and ominous to tell someone that he/she was dying.[3] Moreover, individualism was less important in Chinese culture; family relationships were assumed to be of primary importance,[3] and tended to play a decisive role in a patient's treatment plan. Moreover, the concept of an AD is relatively new and hard to implement in the presence of Chinese cultural attitudes.

On the other hand, there is rising concern about the benefits of the AD in our health care system. Being aware of the importance of this issue, in July 2004 the Government of Hong Kong SAR published a consultation paper on the subject.[4] However, since the public and health care workers were not familiar with the concept, after due consultation the Law Reform Commission did not propose to legislate a scheme for ADs or to define the law on the subject.[4] Instead, the Commission recommended the concept should initially be promoted by non-legislative means and that the Government should review its position once the community had become more familiar with it.

This concept is new, and as yet it may not be accepted in our general population, but we believe that there could be specific groups of Chinese that were more likely to accept ADs and benefit from their implementation. For example, many Chinese elderly living in nursing homes (88%) prefer to have an AD regarding their future medical treatment,[5] but little is known about other groups. We therefore conducted a prospective cohort study to evaluate the acceptance of the AD by Chinese patients with advanced malignancy, and the factors contributing to their decisions.

Methods

Study design

From 24 April 2009 to 30 July 2009, we enrolled patients who were newly referred to our palliative service in a prospective cohort study. The study was performed at the Clinical Oncology Palliative Care Unit of the Tuen Mun Hospital in Hong Kong.

The advance directive form

The AD form was a locally designed one-page document declaring the patient's understanding of their disease status, aims of future treatment preferred, and the refusal of futile treatment. It also included instructions not to initiate cardiopulmonary resuscitation if their condition deteriorated due to malignant disease or its complications, and their agreement to release their wishes to the health care system as well as options of disclosing such wishes to their relatives. It also mentioned their understanding of their rights and the procedure to revoke the AD at anytime. It was signed by the patient and witnessed by a clinician and a nurse. A family notification form was signed by the relative (if available and with the patient's consent).

與末期癌症患者討論預設醫療指示是否可行？一項前瞻性定群研究

目的 預設醫療指示在西方國家已實行多年，但對於亞洲人來說仍是陌生的概念。儘管預設醫療指示對於病人的治療很重要，但受中國文化影響，家人對病人的治療計劃仍有決定性影響力，所以很難實行預設醫療指示。本研究評估預設醫療指示的可行性及找出其重要的決定性因素。

設計 前瞻性定群研究。

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參與者 研究對象為2009年4月24日至7月30日新轉介本院紓緩治療部的末期癌症成人患者。本研究從護士評估表格、本部門設計的預設醫療指示表格、由臨床腫瘤科醫生填寫的清單及醫院電子紀錄取得所需資料。

結果 被納入研究範圍的191名病人中，120人（63%）有預設醫療指示，其餘的71人（37%）則未有。回歸分析顯示，洞察自己預後較差是導致病人選擇預設醫療指示的最重要因素（P=0.001）。雖未達顯著性，但討論預設醫療指示中遭家人反對亦是另一項重要因素（P=0.082）。其餘未達統計顯著性的因素包括年齡、性別、教育、宗教、財政狀況、居住環境、對診斷的理解、喪親之痛的經驗、腫瘤種類、疾病性質、曾經接受電療或化療的次數、照顧者、內部支持者、護士診所就診、臨床心理學家諮詢，及與紓緩護理統籌員的會面。

結論 與末期癌症患者討論預設醫療指示是可行的。當病人知道自己的預後較差時，以及在家人同意的情況下，就是適合與病人討論預設醫療指示的時候。

Quality control

A departmental protocol on making an AD with patients was established before initiating the study. All seven oncologists and 10 nurses involved in this initiative were trained in a workshop on the making of an AD, at which details of the procedure and a standardised format were discussed.

Patients

All the patients entering the study were newly referred to our in-patient palliative care ward or out-patient hospice day centre. They were at least 18 years old at the time of referral and were diagnosed to have a malignancy based on clinical, radiological, or pathological grounds. Moreover, it was required that they had no more impending therapeutic anti-cancer treatments (chemotherapy, targeted therapy, or radical radiotherapy) at the time of recruitment. Mentally incompetent patients or those already in receipt of palliative care were also excluded. All the patients were Chinese and able to read or respond to questions in Chinese. They were followed until they died or up to 23 April 2010, which was 1 year after the first patient was recruited. Patient data (including that of survivors censored up to 23 April 2010) were retrieved and collated.

Materials

The hospice nurses assisted the eligible patients to complete a nursing assessment form written in Chinese, before meeting the oncologist in the palliative care service. The form documented the patient's demographics, family background, and insight into their disease. At each hospice day centre out-patient visit and at every in-patient encounter in the palliative care ward, oncologists completed the checklist for assessing the feasibility of an AD engagement for the corresponding patient. The checklist consisted of inclusion and exclusion criteria and the feasibility of engaging an AD at that visit. To assess feasibility, the oncologist had to confirm that the patient was conscious and clinically fit to give consent, and not obviously depressed. When the patient agreed to discuss the diagnosis and prognosis, the oncologist explored his or her understanding of their health condition. Patient's worries were identified and gaps in knowledge answered. The high possibility of not being able to communicate at the end of life was explained and the preference for treatment such as cardiopulmonary resuscitation was inquired into. If the patient showed his or her preference for a Do Not Resuscitate (DNR) policy, it was considered feasible to discuss an AD. The AD

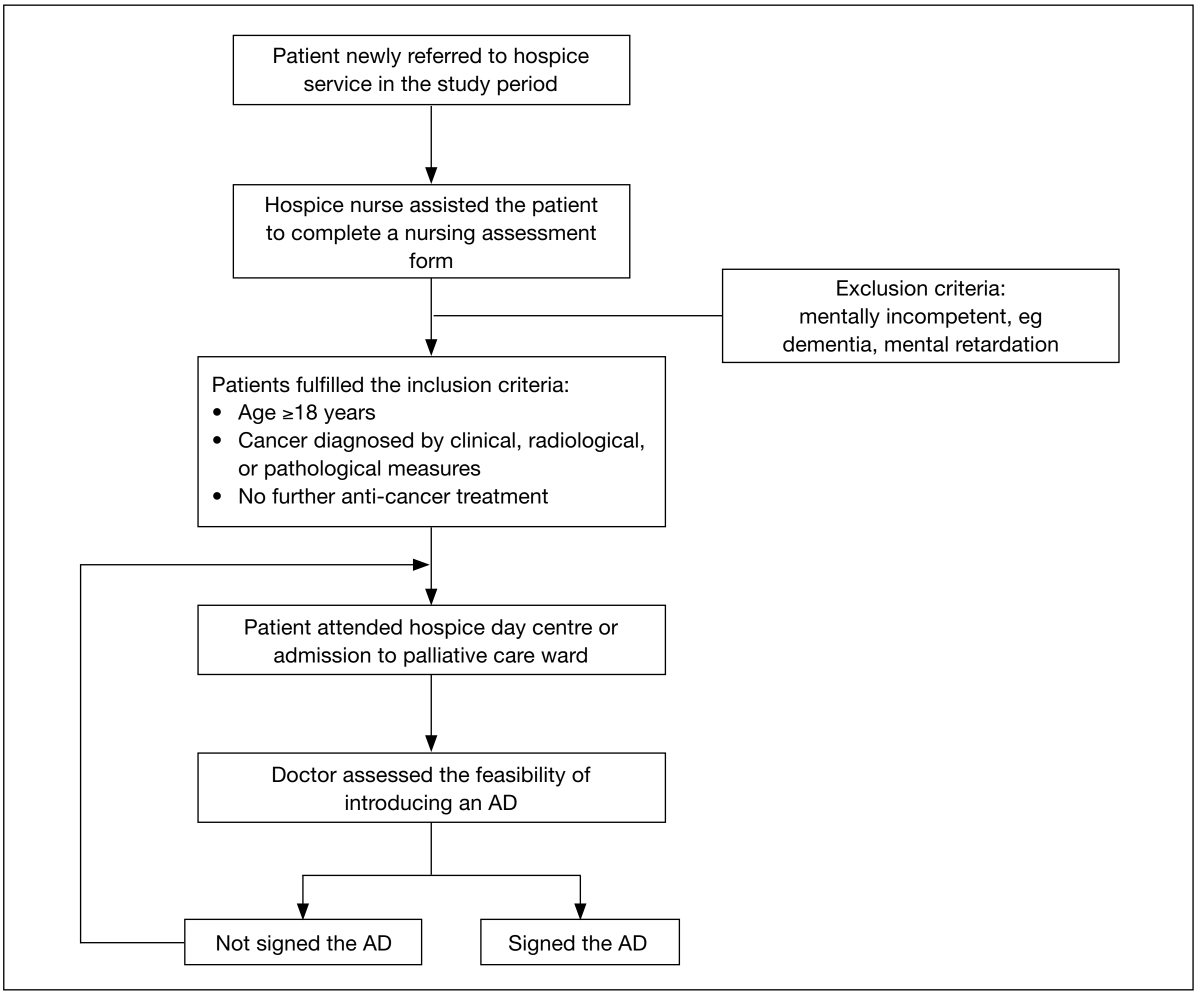

FIG. Workflow diagram
AD denotes advance directive

form was then introduced. If the patient did not show such a preference or was not interested to discuss the topic further, the form was not introduced. If the patient agreed to sign the form, a nurse reconfirmed the patient's conscious level and that the AD was understood, whereupon the form was signed by the patient, the oncologist and the nurse. This meant that the AD was engaged.

If the patient had not engaged an AD, reassessment was undertaken at subsequent visits/encounters (Fig), at which time a new checklist was discussed by any one of the seven trained oncologists in the study.

Family participation

Family members were encouraged to participate in the AD discussion. If the patient was seen alone, he/she was encouraged to discuss the matter with his/her family and if agreed sign the AD at the next encounter. If the patient refused to inform the family about his/her decision on an AD, the patient was counselled to reconsider.

If the patient and family differed on the future treatment plan, counselling was initiated and the hospice nurses tried to achieve a consensus. No matter what, if the patient insisted to engage an AD without informing his/her relative or without a consensus within the family (despite repeated counselling at multiple sessions), the patient's autonomy and privacy was respected. If any family member expressed their objection before or during the AD discussion, their reason was explored and any misconceptions corrected. If the family still insisted, their objection was respected unless the patient initiated the request for AD.

Data on the patient's disease status, types of treatment received, and number of hospitalisations were obtained through the electronic hospital record. The entire study was approved by the Hospital Ethics Committee.

Statistical analysis

The main dependent variable of interest was the presence or absence of an AD. Independent variables included age at recruitment, gender, education, religion, financial status, living environment, the patient's insight (understanding of the diagnosis and the expected prognosis) about their disease before the first palliative intervention, bereavement experience, type of cancer, nature of illness, courses of chemotherapy or radiotherapy received, as well as main caregiver and in-house supporter. Palliative care intervention variables evaluated included nurse-led clinic attendances, clinical psychologist consultations, and in-patient hospice nurse coordinator interviews. These were not counted if administered after the AD had been signed.

Statistical analyses were performed using SPSS software, PASW statistics 18. Univariate analysis among groups was performed using the Mann-Whitney *U* test for continuous data, and Chi squared or Fisher's exact tests for categorical data. If the P value was <0.2 in the univariate analysis, the corresponding variables were included in the Cox regression using the backward stepwise approach.

Results

A total of 268 patients were referred to our Palliative Care Unit within the study period, of whom 191 were eligible according to our study criteria. Data on the excluded patients are summarised in Table 1. Of the 191 eligible patients, 120 (63%) signed an AD, and 71 (37%) did not. Table 2 lists the characteristics of the patients who signed or did not sign an AD. Up to 23 April 2010, 175 (92%) of the patients had died; 16 (8%) were still alive, among whom eight had an AD engaged. No patient revoked their AD.

In the univariate analysis, there were five factors with a with P value of <0.2, including living environment (P=0.115), understanding the diagnosis (P=0.014), expected prognosis (P=0.001), any family objection during the discussion (P=0.064), and clinical psychologist counselling (P=0.15). These factors were included in the Cox regression using the backward stepwise approach.

In the Cox regression model, expected prognosis was highly associated with AD engagement

TABLE 1. Patients excluded from the study (n=77)

Reason of exclusion	No. (%) of patients
Mentally unfit	36 (47)
Planning for or undergoing anti-cancer treatment	18 (23)
Malignancy not confirmed	3 (4)
Not seen by one of the study-assigned oncologists in the first consultation	3 (4)
Physically too ill to attend our service	17 (22)
Total	**77 (100)**

TABLE 2. Clinical and psychosocial characteristics of the 191 patients with or without advance directives (AD)

Variable*	**With AD (n=120)**	**Without AD (n=71)**	**P value**
Age (years)			0.263†
Median	66	71	
Range	37-91	19-91	
Gender			0.947‡
Male	80 (67%)	47 (66%)	
Female	40 (33%)	24 (34%)	
Education level			0.381‡
Illiterate	23 (19%)	19 (27%)	
Primary	51 (43%)	23 (32%)	
Secondary	35 (29%)	16 (23%)	
University	5 (4%)	4 (6%)	
Unknown	6 (5%)	9 (13%)	
Financial status			0.664‡
Non-CSSA	79 (66%)	43 (61%)	
CSSA	35 (29%)	22 (31%)	
Unknown	6 (5%)	6 (9%)	
Living environment			0.115‡
OAH	11 (9%)	15 (21%)	
Public estate	44 (37%)	19 (27%)	
Rental	17 (14%)	8 (11%)	
Self-own	41 (34%)	22 (31%)	
Unknown	7 (6%)	7 (10%)	
Bereavement experience			0.804‡
No	90 (75%)	50 (70%)	
Yes	20 (17%)	10 (14%)	
Unknown	10 (8%)	11 (16%)	
Religion			0.89‡
No	73 (61%)	41 (58%)	
Yes	41 (34%)	22 (31%)	
Unknown	6 (5%)	8 (11%)	
Understanding the diagnosis			0.014§
No	4 (3%)	9 (13%)	
Yes	112 (93%)	55 (78%)	
Unknown	4 (3%)	7 (10%)	
Expected prognosis			0.001‡
Good + fair	32 (27%)	25 (35%)	
Poor	79 (66%)	30 (42%)	
Unknown	9 (8%)	16 (23%)	
Types of cancer			0.824‡
Ca lung	36 (30%)	17 (24%)	
Ca breast	5 (4%)	4 (6%)	
Ca colorectal	24 (20%)	12 (17%)	
Gynaecological	5 (4%)	3 (4%)	
Urological	6 (5%)	6 (9%)	
Gastroesophageal	10 (8%)	7 (10%)	
NPC	2 (2%)	2 (3%)	
H&N	2 (2%)	1 (1%)	
Hepatobiliary and pancreatic	22 (18%)	13 (18%)	
CNS	0	2 (3%)	
Haematological	2 (2%)	0	
Unknown origin	2 (2%)	2 (3%)	
Others	4 (3%)	2 (3%)	

TABLE 2. [Cont'd]

Variable*	With AD (n=120)	Without AD (n=71)	P value
Nature of illness			0.492‡
Distant metastasis	90 (75%)	48 (68%)	
Local advance	20 (17%)	14 (20%)	
Others	10 (8%)	9 (13%)	
No. of lines of chemotherapy given			0.305†
Median	0	0	
Range	0-5	0-5	
No. of radical RT course			0.215†
Median	0	0	
Range	0-2	0-1	
No. of palliative RT course given before signing the wish			0.487†
Median	0	0	
Range	0-3	0-3	
Main carer			0.254‡
Spouse	51 (43%)	22 (31%)	
Children	48 (40%)	36 (51%)	
Others (nil or other relatives or friends)	21 (18%)	13 (18%)	
In-house supporter			0.299‡
Spouse	22 (18%)	14 (20%)	
Children	22 (18%)	8 (11%)	
Spouse and children	44 (37%)	20 (29%)	
Institute	13 (11%)	15 (21%)	
Alone	10 (8%)	8 (11%)	
Others (friend, parent, others)	7 (6%)	4 (6%)	
Unknown	2 (2%)	2 (3%)	
Any family objection during the discussion			0.064§
No	116 (97%)	65 (92%)	
Yes	1 (1%)	4 (6%)	
Unknown	3 (3%)	2 (3%)	
Nurse-led clinic attended			0.658‡
No	101 (84%)	58 (82%)	
Yes	19 (16%)	13 (18%)	
Clinical psychologist counselling			0.15‡
No	67 (56%)	32 (45%)	
Yes	53 (44%)	39 (55%)	
Interviewed by hospice nurse coordinator			0.409‡
No	74 (62%)	48 (68%)	
Yes	46 (38%)	23 (32%)	

* CSSA denotes Comprehensive Social Security Assistance, OAH old-age home, Ca carcinoma, NPC nasopharyngeal carcinoma, H&N head and neck, CNS central nervous system, and RT radiotherapy

† Mann-Whitney *U* test

‡ Chi squared test

§ Fisher's exact test

(P=0.001); if a family objected during the discussion, there was a trend towards rejection (P=0.082). Patients with an expected poor prognosis were more likely to sign the AD (hazard ratio [HR]=1.735; 95% confidence interval [CI], 1.143-2.635). Patients with a family member objecting during the discussion were less likely to engage in an AD (HR=0.217; 95% CI, 0.030-1.576). Other factors did not show any significant effect on AD engagement (Table 2).

Discussion

Our study was important because it was pioneering, and entailed a prospective cohort with significant number of patients in our locality and demonstrated acceptance of ADs. This could be a cornerstone for future developments and serves as a model for engaging an AD in patients with advanced cancer.

Acceptance rate of the AD concept was high in our Chinese patients with advanced malignancy, even against a background of minimal individualism in Chinese culture. The favourable and unfavourable factors we found provide a key to AD engagement. Whenever patients show insight about their poor prognosis and there is no family objection during the discussion, it may be a prime time for considering AD engagement.

In all, 63% of our patients engaged an AD, such rate was higher than that in a previous study on seriously ill cancer patients reporting a rate of 41%.[6] The acceptance rate in our series was unexpectedly high for an Asian cultural group. According to a Taiwan study, the patient preference for end-of-life care was frequently dominated by their families, with the AD rate being only around 18%, while in 82% consent for DNR order was signed only by family members.[7] Data on AD engagement in Hong Kong have been meagre, but there were studies on attitudes towards ADs among Hong Kong Chinese elders with chronic disease[8] and among Hong Kong Chinese nursing home residents,[5] with preference rates as high as 49% and 88%, respectively. Thus, the concept of an AD could be well accepted if suitably promoted and with appropriate education for specific groups or even the public.

One of the most commonly cited barriers to completing an AD was the lack of physician initiatives to discuss with them.[9] Our study provided a platform for oncologists to initiate this important issue with the cancer patients themselves, rather than only with their family members.

Our study also found that patients who comprehend their poor prognosis were more likely to engage in an AD. This is compatible with reports from a Taiwan study indicating that patient awareness of their poor prognosis is one of the most important factors inducing them to sign their own DNR orders.[7] Communication about the issue of prognosis is an essential aspect of effective advanced care planning.[10] When patients have a better insight about their disease, they accept the concept of AD more readily. Our service model had the advantage that most of the discussion was carried out with oncologists, while in other countries like the US, such discussion may initially be carried out by others (volunteers, social workers, chaplains). Patients need to understand their health condition more thoroughly before entertaining the prospect of ADs, and any knowledge gap should be answered directly.

The discussion process for an AD provides a good opportunity to readdress patient confusion about their diagnosis and prognosis before an expected death from cancer. According to one report, 92% of patients felt that mental awareness at the end of life was very important and 96% wished to know what to expect regarding their physical condition in relation to their end-of-life preparations.[11]

When patients are referred to our palliative service, most are informed about the cessation of all active oncological treatment. By this means they understand their diagnosis before meeting our palliative care service and have an insight into their poor prognosis, and hence may be more inclined to engage an AD. However, our study show that objection from a family member may diminish the probability of engagement. In Chinese culture, people fear that openly acknowledging an impending death is like casting a death curse on a person, so to engage in discussions of any such code status or an AD is viewed as courting bad luck. Moreover, families frequently request the health care givers not to disclose the reality of impending death to the patient, thus putting doctors in a quandary when it comes to accurate and complete disclosure of information essential for decision-making about end-of-life care or ADs.[3] We usually try hard to discuss these matters with the family and correct any misconceptions. It is only after family deliberation that the doctors undertook discussing ADs with the patient.

One limitation of our study was that it entailed only a single centre experience of Chinese patients with advanced malignancy. To obtain a more complete picture on AD acceptance in this locality, further studies are needed in multiple centres, other cultural groups, and in patients with non-malignant palliative conditions. Several other factors that may affect AD engagement (such as monthly family income) were not covered in our study. Thus, the high acceptance rate of AD may not be reproducible in other settings. The busy clinic and lack of credit for AD discussion during consultations hinder the promotion of AD in Hong Kong public hospitals. Cooperation with nurses, social workers, pastors, and other health care providers is necessary for AD promotion, as oncologists or physicians alone are not likely to be able to sustain the huge input required.

Feedback from the patients and relatives was also collected and will be published at a future date. Studies on psychological factors affecting AD engagement are also needed.

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