Editorial

Complexities in delivering end-of-life care in accordance with patient desires that have been documented

Kwok Ying Chan[1]^, Desmond Y. H. Yap[2]^, Harinder Singh Harry Gill[3]^, Ho Yan Au[1], Chi Yan Wong[1], Kwok Wai Tsang[1], Man Lui Chan[4]

[1]Palliative Medical Unit, Grantham Hospital, Hong Kong, China; [2]Division of Nephrology, Department of Medicine, Queen Mary Hospital, University of Hong Kong, Hong Kong, China; [3]Division of Haematology, Medical Oncology and Haemopoietic Stem Cell Transplantation, Department of Medicine, The University of Hong Kong, Hong Kong, China; [4]Department of Psychiatry, The Chinese University of Hong Kong, Hong Kong, China

Correspondence to: Dr. Kwok Ying Chan, MD, MRCP, FHKCP. Palliative Medical Unit, Grantham Hospital, 125 Wong Chuk Hang, Hong Kong, China. Email: cky842@yahoo.com.hk.

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It is commonly acknowledged that patients' ultimate goals and the treatment they receive near the end of life frequently diverge dramatically (1). For instance, even though the majority of participants stated that more over 70% of those mentioned they would prefer to die at home actually did it in hospitals, where they would have received more invasive or inappropriate care (1,2). Therefore, it appears that patient management is still actively treating patients for cures rather than honoring their wishes for end-of-life (EOL) care (3). In fact, some patients with metastatic or terminal illnesses may experience agony or distress as a result of unneeded procedures because they did not discuss their choices for EOL care with the treating physician (3).

Advance care planning (ACP) discussions are a helpful process to improve EOL care by better organizing and providing the patients' care in a way that satisfies their requirements and preferences. ACP dialogues are crucial exchanges that have the potential to influence our practice and empower our patients. Making decisions for the patients during an ACP session typically takes some time (for example, dialysis treatment). Individuals interested in providing palliative and EOL care could play a vital role in the ACP discourse with further training will have an advantage in facilitating the dialogue (1).

Patients can indicate their expectations for the kind of care they expect to receive at the EOL through the advance statement in the ACP, which may include decisions or refusals of specific medical care, including cardiopulmonary resuscitation and some intensive treatments (4). Through the ACP process, it might be useful to clarify patients' objectives and preferences in advance of anticipated future decline and mental disability. This will guarantee that the EOL care expectations of patients with advanced cancer or end-stage organ failure who chose conservative therapy can be honored. It can be challenging for the professionals caring for these medically ill individuals to learn their preferences, especially for those without relatives (5). There is a potential that their clinicians won't be ready to make informed choices, which could lead to disagreements between various parties. In these circumstances, there is no documentation of the patient's wishes, expectations, or resuscitation status when they reach EOL and become mental incompetent in the dying phase, although most medical staff are well aware of the needless conflicts and

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^ ORCID: Kwok Ying Chan, 0000-0002-2521-297X; Desmond Y. H. Yap, 0000-0001-8179-8293; Harinder Singh Harry Gill, 0000-0002-9551-4893.

invasive interventions in hospital settings (5). According to one randomized controlled trial, patients in the ACP group were more likely to have their EOL preferences recognized and respected, and their family members also stated that the patients were less nervous or unhappy (6). A thorough assessment also showed that ACP could enhance patient and family satisfaction throughout the course of medical care (7).

Notably, the majority of patients with advanced cancers and medical illnesses still lack ACP, especially when disease-modifying medications are present.

Thus, it would be appropriate for mapping the barriers to ACP. Cabana and colleagues used a framework comprising knowledge, attitudes, and behavior to address the barriers preventing physicians from adhering to clinical guidelines (8). Other studies have outlined a number of obstacles to providing EOL care in accordance with recorded patient preferences. It has demonstrated that doctors typically support preferences listed in the ACP guidelines more when they are consistent with their clinical judgment and less when they are inconsistent with their treatment plan (9). In addition, one study showed that patients with advanced cancer/end organ failure patients have demonstrated that patients' preferences alter throughout time (10). The treating physician may not be able to claim with certainty that the preference documented in the ACP document is what the patient may have wished at that point in time if patient preferences change over time and ACP talks are not routinely repeated. Moreover, a lack of resources may make it difficult to provide EOL care that is in line with preferences (11). Furthermore, research indicates that clinicians have trouble locating patient wishes in medical records when deciding whether to EOL care (4,12). Studies have also demonstrated that structured ACP programs with in-depth training and public participation can change the culture of healthcare organizations to reflect patient preferences (4,13).

Elderly patients with dementia might have more complexities in achieving their EOL preferences. For instance, despite the relatively high proportion of residents who had completed do-not-hospitalize (DNH) orders at baseline, a study of 38% of surrogates still expressed a preference for care that included hospitalization, parenteral antibiotics, and hydration; the intervention had no effect on these care preferences at any point during follow-up (14). The goal of ACP is to harmonize patients' care preferences with their values and aspirations, not to alter well-informed preferences. The fact that the intervention had no impact on patients' care preferences or DNH orders may simply be an indication that patients' declared values and aims had a stable influence on their choices. This finding also indicated some of the limitations of using ACP intervention (e.g., video assisted) in isolation to address the difficulties associated with ACP for dementia patients who are nearing EOL. Effective ACP interventions in late-stage dementia should assist the surrogate in identifying the patient's values and navigating morally challenging healthcare decisions by using substituted judgment (with its inherent limitations). The intervention undoubtedly aid in this, but they might not adequately mask the emotional undertones of these difficult choices. Making judgments under stressful circumstances is emotionally taxing, and decisions involving artificial nourishment and hydration in particular frequently elicit strong reactions, particularly when they touch on cultural, social, and religious values.

In addition to ACP interventions according to the stage of the disease, system-level constraints that currently prevent the implementation of care preferences must be overcome in order to lessen the costly treatments associated with advanced dementia. Systems of care must make sure that preferences are communicated to everyone involved in a patient's care. Additionally, external reporting of quality metrics must encourage care that is goal-concordant (14).

In a recent study, Malhotra and colleagues enabled a thorough examination of healthcare providers (HCPs)' opinions on ACP implementation (15). Five themes were conceptualized describing the challenges in implementing EOL consistent with patients' documented ACP preferences. This qualitative study showed different viewpoints which could not be obtained in a formal survey. It revealed the difficulties in facilitating EOL care in accordance with patients' recorded ACP preferences. These findings had significance for bettering future ACP program implementation. This study demonstrated that physicians and families, who have the authority to disregard patients' recorded wishes, must demonstrate a significant level of buy-in if patient autonomy shall be respected. Families and/or doctors might find it difficult to "let go" of the patient or they might feel that a particular course of treatment is "standard of care" and in the patient's "best interests".

There are several limitations of this study. Prior research with advanced cancer patients/heart failure patients has demonstrated that patients' preferences can shift over time. Rather than taking into account what they are likely to encounter in the future, patients frequently base their future ACP decisions on their current experiences. This is referred to as "projection bias" (16). The most recent findings also demonstrate how rarely ACP materials are reviewed and changed to reflect patients' evolving desires. Thus, systematic procedures should be incorporated into future ACP implementations to make it a dynamic program rather than a one-time intervention. Additionally, the research excluded non-medical aspects of ACP (financial, burial, etc.) that could affect decisions about EOL care.

To enable them to view their mission as primarily delivering patient-centered care rather than primarily healing illness and extending life, doctors must undergo a mentality change. This is particularly important in complex acute care settings when a number of medical teams collaborate on patient care and treatment choices. Much has to be done to mainstream ACP conversations and educate the public about its advantages (17). Even though it might not always be possible or wise to provide EOL care in accordance with their preferences, future ACP programs should involve physicians and families for ongoing conversations, frequently update patients' ACP documents, include clear and well-resourced plans for implementing patients' preferences, and incorporate a well-designed and flexible electronic system to capture ongoing or incomplete conversations.

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