

Original Article

Advance Care Planning in a Multicultural Family Centric Community: A Qualitative Study of Health Care Professionals', Patients', and Caregivers' Perspectives

Sumytra Menon, LLB(Hons), LLM, Marijke C. Kars, PhD, RN, Chetna Malhotra, MD, MPH, MBBS, Alastair V. Campbell, MA(Hons), BD, ThD, and Johannes J.M. van Delden, MD, PhD

Centre for Biomedical Ethics (S.M., A.V.C.), Yong Loo Lin School of Medicine, National University of Singapore, Singapore, Singapore; Julius Center for Health Sciences and Primary Care (M.K., J.J.M.v.D.), University Medical Center Utrecht, Utrecht, The Netherlands; and Lien Centre for Palliative Care, Duke-NUS Medical School (C.M.), Singapore, Singapore

Abstract

Context. Advance care planning (ACP) has been shown to improve end-of-life care, but it was developed in the U.S., and most research has been conducted in western communities.

Objectives. We aimed to study the attitudes and perceptions of patients with life-limiting illnesses, informal caregivers, doctors, nurses, and medical social workers regarding ACP in a multicultural family centric community.

Methods. We conducted an explorative qualitative study, using focus groups and individual in-depth interviews. We used purposive sampling techniques to recruit 61 adults (15 doctors, 13 nurses, 5 medical social workers, 15 patients, and 13 caregivers) from multiple health care settings across the country.

Results. The participants are genuinely anxious about the implementation of ACP. They had positive and negative expectations of ACP. Many were confused about the legal framework for health care decision-making and expected ACP to be of limited value because family members, rather than the patient, were usually the key decision makers.

Conclusion. A nuanced approach to ACP that considers the family network is required in multicultural family centric communities. Policies should be reconciled to create a more consistent message that respects patients, the family, and is legally coherent. Further research could focus on adaptations of ACP to promote its acceptance in such communities. *J Pain Symptom Manage* 2018;■:■-■. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Advance care planning, advance directives, decision-making, terminal care

Introduction

Advance care planning (ACP) is an ongoing communication process between the patient, health care professionals (HCPs), and/or ACP facilitators involved in the patient's care, and if the patient wishes, the patient's caregivers.^{1,2} Participating in ACP may help patients plan and make decisions for their future health care options based on their values and preferences. If the patient loses capacity to make the specific health care decision, the information in the advance

care plan (ACP) can help guide HCPs and the patient's caregivers to make decisions consistent with patient preferences. ACP improves the likelihood that patients receive end-of-life care that is consistent with their preferences.³

ACP originated in the U.S.^{4,5} Singapore (the setting of this study) has adopted the Respecting Choices ACP framework.⁶ An informational web site explaining ACP for members of the public is available, but there has been no public campaign to promote ACP in Singapore.⁷

Address correspondence to: Sumytra Menon, LLB(Hons), LLM, Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore, Block MD11, #02-03,

10 Medical Drive, Singapore 117597. E-mail: sumy.menon@nus.edu.sg

Accepted for publication: May 8, 2018.

Research on ACP has primarily been conducted in western countries, where the western perspective of autonomy, nonmaleficence, and beneficence is prevalent. Little is also known about the impact of ACP in a more family centric Asian society, where individual autonomy is less important than the family's overall interests.⁸ And even less is known about how patients with life-limiting illnesses, their caregivers, and HCPs perceive ACP. This information is essential for the ACP program in Singapore to succeed (Table 1). A few studies conducted locally on ACP have focused on specific disease areas, for instance, renal failure and cognitive impairment, and consequently, their results are unlikely to be generalizable to patients with other life-limiting illnesses.^{11–13} These studies revealed that patients and caregivers were reluctant to engage in ACP because they thought their relatives would make decisions for them when they lose capacity, and HCPs thought patients would decline to talk about such matters because of its association with death.

Therefore, the objective of our study was to learn about the attitudes and perceptions of patients with life-limiting illnesses, informal caregivers, and HCPs (collectively described here as participants) in multicultural and multireligious Singapore regarding ACP.

Methods

Design

We conducted an explorative qualitative study, using focus groups (FGs) and individual in-depth interviews (IDIs).¹⁴ After reviewing the existing literature, the research team developed a semistructured interview guide for the FGs (Appendix I).

Setting, Participants, and Sample

We used purposive sampling techniques to recruit patients with a life-limiting illness, informal caregivers

of such patients, and HCPs (all adults older than 21 years).

Through the heads of various health care institutions across Singapore, and the government secretariat responsible for implementing ACP, we invited HCPs from specialties likely to care for patients with life-limiting conditions, such as geriatrics and family medicine to participate in this study (details in Appendix II). The HCPs who were recruited as participants were not the same HCPs who assisted with recruiting participants who were patients and caregivers. Patients with a life-limiting condition were recruited because we thought this group would be most receptive to ACP and had the greatest need for it. We did not limit recruitment to any specific condition. Informal caregivers were recruited if they were caring for or had cared for a loved one. They were not related to patients who participated in our study. We did not recruit patient-caregiver dyads because it would have been too challenging to do so given our recruitment method. Patients and informal caregivers were recruited from a variety of health care institutions and settings with the assistance of their health care providers (details in Appendix II). All participants gave informed consent before the FGs were conducted.

Data Collection

The moderator used the questions in the interview guide as a starting point for discussion and followed up with probing questions based on the participants' responses. Participants were also encouraged to discuss and debate the responses to the questions among themselves so the ensuing discourse revealed their thoughts and feelings. We conducted separate FGs for doctors only and for nurses and medical social workers (MSWs) because of concerns that hierarchical issues could inhibit a nurse or an MSW from speaking up in a group with doctors, and thereby biasing the responses.¹⁵

Table 1

Brief Background of Singapore and its Law on Health Care Decision-Making

Singapore is an island state with a population of 5.5 million. It is a multicultural and multiethnic society. The majority ethnic group is Chinese, and minorities include Malays and Indians. The main religions include Taoism, Christianity, Islam, and Hinduism. There is no specific law in Singapore on ACP. The Advance Medical Directive Act passed in 1996 allows competent adults to complete a prescribed form to refuse extraordinary life-sustaining treatment in the future if they are terminally ill and at imminent death.⁹ It is a criminal offense for health care professionals to ask whether a patient has an AMD. The rationale for this was to allay concerns that someone who had an AMD could receive less care than someone who did not. Singapore also has the MCA of 2008, which allows competent adults (donor) to make an LPA appointing a proxy decision-maker (donee) for health care decisions.¹⁰ However, the donee cannot make decisions on life-sustaining treatment or treatment to prevent a serious deterioration in the donor's health. The doctor makes those in the patient's best interests. The MCA requires the doctor to consider the preferences and wishes of patients, so far as it is reasonably ascertainable, and the views of donees and loved ones, if practicable and appropriate, when making such decisions. An advance care plan is different from an AMD because it can cover a wide range of health care matters, and although the patient's preferences and wishes should be honored, there is currently no statute or case law requiring it. However, a decision taken in the best interests of an incompetent patient, as required under the MCA, would usually align with the patient's preferences and wishes.

Download English Version:

<https://daneshyari.com/en/article/8605414>

Download Persian Version:

<https://daneshyari.com/article/8605414>

[Daneshyari.com](https://daneshyari.com)