

Original Article

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# Patient autonomy and participation in end-of-life decision-making: An interpretive-systemic focus group study on perspectives of Asian healthcare professionals

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## Abstract

**Objectives.** Asia's first national advance care planning (ACP) program was established in Singapore in 2011 to enhance patient autonomy and self-determination in end-of-life (EoL) care decision-making. However, no known study has examined the extent to which ACP in Singapore successfully met its aims. The purpose of the current study was to examine the attitudes of local healthcare professionals on patients' autonomy in decision-making at the EoL since they strongly influence the extent to which patient and family wishes are fulfilled. **Methods.** Guided by the Interpretive-Systemic Framework and Proctor's conceptual taxonomy of implementation research outcomes, an interview guide was developed. Inquiries focused on healthcare professionals' attitudes towards ACP, their clinical experiences working with patients and families, and their views on program effectiveness. Sixty-three physicians, nurses, medical social workers, and designated ACP coordinators who were actively engaged in ACP facilitation were recruited from seven major hospitals and specialist centers in Singapore through purposive sampling. Twelve interpretive-systemic focus groups were conducted, recorded, transcribed, and analyzed using a thematic analysis. **Results.** The extent to which patients in Singapore can exert autonomy in EoL care decision-making is influenced by five themes: (i) collusion over truth-telling to patient, (ii) deferment of autonomy by patients, (iii) negotiating patient self-determination, (iv) relational autonomy as the gold standard and (v) barriers to realization of patient choices. **Significance of results.** Healthcare practitioners in Asian communities must align themselves with the values and needs of patients and their family and jointly make decisions that are consistent and congruent with the values of patients and their families. Sensitivity towards such cross-cultural practices is key to enhancing ACP awareness, discourse, and acceptability in Asian communities.

## Introduction

Derived from the Greek word *autos*, that is, the self, and *nomos*, that is, laws, the term “autonomy” is commonly understood as related to self-governance and self-determination (Harnett and Greaney, 2008). Particularly within the domain of healthcare, recognition of and respect for the autonomy that patients have to make decisions regarding their treatment and care is a core ethical value; yet protecting patients' autonomy can be challenging because illness can make individuals dependent on the care and decisions of others, thereby reducing their autonomy and making them susceptible to manipulation by those on whom they are dependent (McLeod and Sherwin, 2000). Some studies have pointed out that the rather simplistic notion of total autonomy of the individual patient may not accurately reflect the process of end-of-life (EoL) decision-making, particularly when working with patients from diverse cultural backgrounds (Searight and Gafford, 2005; Entwistle et al., 2010; Kai et al., 2011). Over-emphasis on patients' independence to make decisions regarding their care undervalues the interpersonal relationships and broader relationships within which patients are situated (Entwistle et al., 2010). More recently, there has been a discourse about a “relational” understanding of autonomy, which emphasizes the web of social relationships and determinants within which individuals are situated (Walter and Ross, 2014). However, these studies have been conducted only in the

West, resulting in a dearth of understanding about patient autonomy and decision-making in the Asian context.

Advance care planning (ACP) is increasingly recognized as a core component of patient-centered care in medically advanced nations (Brinkman-Stoppelenburg et al., 2014; Johnson et al., 2017). ACP extends patient's autonomy and self-determination by making known the type of care they would prefer if they become very ill and are unable to make health care decisions in the future (Ikonomidis and Singer, 1999; Brinkman-Stoppelenburg et al., 2014; Johnson et al., 2017). A number of arguments have been raised regarding the acceptability of ACP in culturally diverse societies (Searight and Gafford, 2005; Johnstone and Kanitsaki, 2009; Collins et al., 2018); specifically, ethnic-minority families may perceive advance directives to be an intrusive legal mechanism of the mainstream culture which interferes with their responsibility to care for their loved ones; while ethnic-minority patients fear that completing an ACP would result in them being left to die even when medical intervention could improve health outcomes.

In Singapore, the Ministry of Health works with the Agency for Integrated Care, to promote a national ACP program that began since 2011 (Irwin and Chung, 2010). ACP in Singapore was conceptualized to pave the path for holistic EoL care service delivery and promote quality of life for patients at EoL by empowering them to make decisions regarding their own care ahead of crisis times when they are no longer able to make decisions (Lien Centre for Palliative Care, 2011; Advance Care Planning, 2019). More than 7 years since the implementation of ACP in Singapore, there is no known study which examines how local healthcare professionals perceive ACP and the extent to which ACP does in fact enhance patients' autonomy and their participation in EoL decision-making. The present study addresses this knowledge gap.

## Methods

### Sampling and data collection

This study is part of a formal evaluation of Singapore's national ACP program. Ethical approval for this study was obtained from Nanyang Technological University's institutional review board [Ref: IRB-2016-05-023] and the National Healthcare Group's Domain Specific Review Board [Ref: 2016/00603]. To attain a holistic understanding of the dynamics and mechanisms that underscore Singapore's ACP program, the Interpretive-Systemic framework (Fuenmayor, 1991) was adopted to guide the process of inquiry. This involved eliciting perspectives of all professional stakeholders who played critical roles in and were affected by the ACP program, of which included physicians, nurses, social workers, and allied health workers hired specifically for the role of ACP coordinator. This multi-level framework of inquiry enables a systemic understanding of ACP development and implementation through the interpretive lens of different stakeholder groups that belong to the diverse contextual systems of health and social care (Ochoa-Arias, 1998).

Participants were purposively recruited via email contact by on-site Principal Investigators attached to all seven major local acute healthcare settings that were responsible to implement ACP in Singapore. The participating healthcare institutions include Changi General Hospital, Tan Tock Seng Hospital, KK Women and Children's Hospital, National Heart Centre, Khoo Teck Phuat Hospital, National University Hospital, and Singapore General Hospital. Twelve Focus Group Discussions (FGDs) were conducted

**Table 1.** Demographic details of participants

Vocation groups	N	Age (range)	Gender	Ethnicity
Physicians	12	30–60 (SD:11.61)	1 M	11 Chinese
			11 F	0 Malay
				0 Indian
				1 Others
Nurses	15	27–63 (SD:10.80)	1 M	11 Chinese
			14 F	3 Malay
				1 Indian
				0 Others
Medical social workers	24	26–49 (SD: 7.50)	4 M	22 Chinese
			20 F	2 Malay
				0 Indian
				0 Others
ACP coordinators	12	25–58 (SD: 9.00)	5 M	11 Chinese
			7 F	1 Malay
				0 Indian
				0 Others
All groups	63	25–63 (SD: 9.48)	11 M	55 Chinese
			52 F	6 Malay
				1 Indian
				1 Others

with 63 healthcare professionals, of which include, doctors ( $n = 12$ ), nurses ( $n = 15$ ), Medical Social Workers (MSWs) ( $n = 24$ ) and designated ACP coordinators ( $n = 12$ ) from these participating hospitals. All participants received formal ACP training and were responsible for the facilitation of ACP discussions with the patients that they served, particularly those patients who had been diagnosed with chronic life-threatening illnesses. Participants' demographic characteristics are shown in Table 1.

The focus of the inquiry of each FGD was the conceptual taxonomy of implementation outcomes (Proctor et al., 2011). Proctor's taxonomy is conceived as the impact actions taken to implement a new intervention program, with conceptually distinctive outcomes to assess successful implementation. This study employs the five outcomes of acceptability, fidelity, feasibility, penetration, and sustainability to elicit participants' experiences in ACP delivery. Sample discussion questions included (i) How do you initiate an ACP conversation with patients? (ii) How do patients and their families respond to ACP? (iii) What are some of the challenges you face in meeting patients' preferences? (iv) What according to you constitutes a successful ACP discussion? All FGDs were conducted in October 2016, in a safe space that was conveniently accessible from participants' workplace. Informed consent was collected at the beginning of each FGD, each FGD lasted 1.5–2 h, of which was audio-recorded, transcribed verbatim, checked for accuracy before analysis.

### Data analysis

All audio recordings were transcribed using Microsoft Word and imported into QSR NVivo 11 for analysis. Thematic analysis was

adopted to identify, analyze, and report patterns that emerged within the data; specifically, how individuals' subjective realities were influenced by the range of discourses prevalent in society (Braun and Clarke, 2006). This approach involved the development of "themes" — a patterned response or meaning within the data which captured something important about the data in relation to the research question (Pope et al., 2000). Our thematic analysis was theoretical in nature, scrutinizing an aspect of the data based on the research team's analytic interest in that area (Braun and Clarke, 2006). Further, data analysis went beyond mere semantic content to examine the latent ideas that shaped the semantic content of participants' quotes. Trustworthiness and credibility of the analysis were ensured through the maintenance of an audit trail, debriefing sessions among the research team to discuss evolving interpretations and test alternative notions, inter-researcher consensus, achievement of data saturation, and site triangulation.

## Results

All participants were recipients of the same ACP training provided by the Agency of Integrated Care in Singapore. Hence, it is not surprising that participants tended to agree with each other on the philosophy underlying ACP in Singapore, particularly the notion of individual autonomy as a central tenet of patient-centered care. However, despite this seeming consensus over the benefits of ACP for patients, there were differences between professionals in their understanding of autonomy. Particularly, physicians tended to be governed by the belief of their roles to determine the extent to which patients are given the choice to decide on their own health care and EoL decisions. This is attributed by the physicians' prevailing insights on patient's medical conditions and treatment options, as seen from the themes below.

Findings showed that within the local context, the degree to which a patient had the freedom to make healthcare and EoL decisions for him/ herself was a complex process influenced by multiple, often-competing forces. These include collusion over truth-telling to patient, deferment of autonomy by patients, negotiating patient self-determination, relational autonomy as the gold standard and barriers to the realization of patient choices.

### **Theme 1: Collusion over truth-telling to patient (number of FGDs theme appeared in; N = 8)**

Participants explained that negotiated agreements between healthcare professionals and the patient's family to moderate the information to the patient were a common phenomenon. They highlighted the prevalent belief among families that patients were not ready to accept the state of their health and therefore needed protection from emotional suffering associated with a terminal diagnosis. This also underscored the local trend of attributing greater value to the decision of the family and the physician, rather than the patients themselves.

They know the patient more and how the patient has previously dealt with bad news ... when the family requests us to not disclose, it is from an angle of love and protection. And I think our job is to first find out a bit more, where they are coming from and approach it accordingly. (Doctor, male)

Furthermore, families insisted on withholding illness-related information to prevent the patient from feeling upset about the

seriousness of their condition and their impending mortality. This was especially common in the case of elderly patients.

They still have the concept that it is better not to let my mum or dad know, because maybe, when you tell them, they could become despondent, they could lose their hope or will to live on. (Nurse, female)

The request to not disclose could also suggest a family's underlying motivation to avoid confronting their own psychological pain brought on by the patient's terminal prognosis.

I guess it is for them to face up to their own fears before they can face up to [their] dad [and] tell [their] dad, 'You have cancer.' (Nurse, female)

Lastly, the act of collusion reflected the paternalistic nature of Asian families, wherein decision-making freedom of a patient was restricted in their perceived interest.

There is a lot of concealing diagnoses to elderly patients because they (the patient's family) don't want them (the patient) to feel upset [ ... ] So usually, in Singapore, if we want to break bad news, we speak to the main spokesperson first, discuss it with them, and break the bad news together with the main spokesperson. (Doctor, female)

### **Theme 2: Deferment of autonomy by patients (N = 7)**

This refers to the locally occurring practice of patients relegating their decision-making power to the perceived expertise of others, who are presumed to have more knowledge than they did.

They (patients) don't want to actually assume too much responsibility on their side. (Nurse, female)

Participants highlighted that Asian patients tended to attribute a high degree of authority and deference to physicians and obey recommendations unquestioningly.

Because patients are very obedient, they listen to doctors. 'Doctor asked me to do this, I must do [it].' (ACP coordinator, female)

Elderly patients especially had a strong expectation for familial decision-making in case of long-term care and often abdicated their decision-making powers and nominated their children to make health decisions on their behalf, since they assumed their children to be more knowledgeable on such matters.

A lot of times, they (patients) say, 'Please talk to my son, please talk to my family, they know more and they are in control of my health matters.' (Doctor, male)

### **Theme 3: Negotiating patient self-determination (N = 9)**

Regardless of their profession, participants expressed some degree of belief in and adherence to the doctrines of patient self-determination and affirmation of patients' personal preferences. Often, they served as advocates for patient autonomy in making healthcare decisions and negotiated with families regarding the extent to which illness-related information could be shared with patients.

I speak to the main spokesperson first ... I try my best to convince them that the patient needs to know about the diagnosis. (Doctor, female)

Some participants were advocates of the patient's wishes and preferences in ACP discussions, regardless of whether they aligned with those of the family.

When the family members come in, I make it clear that they are proxy, they are spokesperson to be, that they make decisions for the patient based on his/her guidelines. (MSW, female)

Others insisted on reasoning with the family when family members voiced concerns about relaying a terminal diagnosis to the patient.

When my patient's family tells me, "don't tell my mum that she has cancer," my reply to them [is], "She is going to a clinic, it says 'Cancer clinic,' she is going to be seated with chemotherapy patients, what do you think she is going to think?" (MSW, female)

Still other participants injected subtlety into truth-telling but would not ratify complete violation of honesty to the patient, thereby reaching a middle ground that satisfies both fears about full disclosure and the patient's right to information about their condition.

If it is cancer, then sometimes we say, "There is a tumor growth and that tumor growth cannot be excised or treated ..." and what are the things that are expected with this illness. (Nurse, female)

#### **Theme 4: Relational autonomy as the gold standard (N = 11)**

Providing a platform for patients to acknowledge the role of their family in making important decisions regarding their care was perceived to be the gold standard of EoL conversations by healthcare professionals. Thus, the best possible outcome of an ACP facilitation session was described by participants as one in which patients could exercise their relational autonomy.

The patients have their own decision, but they also want to hear from their family, hear their thoughts [ ... ] it is a collective decision-making. So, [it] is not like in the U.S. where everything is on the patient, and the patient decides on their own. (ACP coordinator, female)

Facilitating discussions about care plans between the patient and the family allowed the preservation of harmony in the family.

The discussion provides an avenue for patients and their families to get together, get to know what each other want, and perhaps come to a consensus or reconcile their differences. (Nurse, female)

Further, the Confucian virtue of filial piety, specifically, children's ability, and resourcefulness to care for their elderly parents also shaped healthcare decisions within the family. Although elderly patients wished to die in the comfort of their home, their children felt obligated to hospitalize them and seek aggressive treatment options to combat the illness.

They (patients) want to die at home because [it] is a familiar surroundings, but the children put the pressure and blame on themselves if we {healthcare professionals} do not do our best. (MSW, female)

Thus, patient autonomy in the local context was found to be relational in nature; it recognized and protected the needs and preferences of all patients and families who sought medical care, along with the dynamics of their interactions. The assumption that an ideal decision regarding treatment and care is one that resonates with all family members implied that healthcare professionals needed to facilitate discussions and negotiations between family members when there were differing viewpoints.

When we get a lot of conflict between brothers and sisters, we have to keep trying to draw them back to say, '[it is] not about you, but about the mom or the dad.' (ACP coordinator, female)

Thus, the Western concept of total patient autonomy on which current models of ACP and EoL decision-making are founded does not align itself with the collectivist worldviews of Asian care-recipients. A collectivist notion of autonomy dominates the Asian mind-set because of the cultural orientation towards the extended family as opposed to individual patient self-interest. However, while relational autonomy in decision-making is upheld as the ideal standard, there are in fact numerous obstacles that prevent this factor alone from guiding care choices, as elucidated in the subsequent theme.

#### **Theme 5: Barriers to realization of patient choices (N = 8)**

Participants perceived it their responsibility to guide patients to make choices that could be met within the constraints of the psycho-socio-economic environment in which the patient was situated. Specifically, the family's emotional competency to care for a dying member, community services that supported the fulfillment of wishes expressed by the patient, and the financial cost of specialized healthcare determined the degree to which the original wishes expressed by the patient would be met. Often, a patient is advised to consider the feasibility of his/her choices and invited to rethink his/her care preferences such that they could be supported by the available resources.

Family [is] reluctant to bring the patient home, even [if] the patient wishes to die at home because of the lack of supportive care, eventually the patient dies in the hospital. (MSW, female)

Additionally, participants elaborated upon the challenges of home care for EoL patients, which could compel families to have the patient die in an institution despite their wish for a home death.

Supportive services [are] not very much in place. [From my] personal experience, hospital bed with air mattresses and O2 concentrator, I think upfront it is going to cost you about eight grands. Add that to a family in trauma, coping with the upcoming loss of their loved ones is a big thing. (MSW, male)

The financial burden of institutionalized care for the elderly also pressurized families to opt for home care despite the challenges associated with the latter.

They ask for nursing home or old folks' home because they have no idea. They are naïve as to how much it actually costs. When the social worker started talking to them about the actual cost, monthly, of placing [the patient] in the nursing home, they said reluctantly that we would bring [the patient] home. (Doctor, male)

## **Discussion**

This novel study examined Asian healthcare professionals' attitudes towards patient autonomy and participation in EoL care, which influences the extent to which patient and family wishes are fulfilled at the EoL. Thematic analysis of the data revealed that healthcare professionals perceived patient autonomy to be a negotiation between various aspects, including: (i) the extent to which illness-related information is disclosed to the patient, (ii) the value attributed by patients to the expertise of the



physician and family members in making healthcare decisions, (iii) the role of healthcare professionals in advocating patient self-determination, (iv) acknowledgement of the trend of relational autonomy in making important health-related decisions, and (v) the degree to which practical support is available in the community to honor the patient's wishes. In contrast to total autonomy of the individual patient, Asian healthcare professionals perceive patient autonomy to be collective in nature, whereby decisions regarding healthcare are the product of a dialog between the patient, their family, and healthcare professionals.

Findings align with previous research (Tan and Farley, 1987) that regardless of modern Western influences, Asian societies even today are guided by traditional family values and the need to avoid conflict within the larger group with which one identifies. When Western viewpoints such as total patient autonomy (Ikonmidis and Singer, 1999) are enforced in such settings, it leaves little room for families of patients to assert their preferences regarding what they want for their loved ones, implying instead that EoL care decisions are made independent of the patient's sociocultural context, past experiences, relationships, and concern for others (Robins-Browne et al., 2014). Further, similar to previous studies (McLaughlin and Braun, 1998; Lai, 2009), belief in filial obligation to care for elderly members and provide resources for their care emerged as an important value in our study. For cultures governed by filial values, the question of "who decides" in healthcare decision-making is not straightforward. A relational understanding of autonomy (Walter and Ross, 2014), which recognizes the social dimensions of an individual patient's agency was found to be fitting in the Asian setting. Moreover, findings indicate that Asian patients, particularly the elderly, rely on the perceived knowledge of their family and the perceived expertise of the physician to make decisions on their behalf. This coincides with findings from other studies on Asian populations (Bowman and Singer, 2001) and sharply contrasts with practices of American patients who are increasingly critical of the authority of medical professionals (Schlesinger, 2002). Overall, findings support literature that the most critical aspect of healthcare decision-making in the Asian context is harmony between family members (McLaughlin and Braun, 1998). Therefore, similar to previous studies (Werth et al., 2002; Schim et al., 2007), it is suggested that Western models of health and palliative care need to be culturally sensitized before they are indiscreetly introduced in societies that are philosophically different from those in which they were conceptualized. Following from earlier research (Doorenbos and Nies, 2003; Johnstone and Kanitsaki, 2009), it is urged that more empirical studies be conducted which examine cultural influences on patient choices in EoL care and address cross-cultural considerations involved in ACP for diverse populations.

Findings further reinforce the common practice within Asian healthcare systems of making privately negotiated agreements between clinicians and the patient's family to moderate or even omit pertinent information regarding a patient's life-threatening diagnosis (Chaturvedi et al., 2009; Low et al., 2009; Krishna and Menon, 2014). While such acts may be intended to protect loved ones from the distress associated with a terminal diagnosis, to preserve hope for a cure, and to fulfill one's filial duty to care for family members, collusion can place healthcare professionals in a tight spot between the patient-centered care, respect for the individual and concerns about inflicting psychosocial harm on their patients (Krishna and Menon, 2014). With a view to safeguarding the ethical principles of healthcare provision, healthcare professionals can explore potential reasons for collusion with the

family, ask relevant questions to elicit the patient's view of what may be happening to him and facilitate interpersonal communication between patients and their families (Chaturvedi et al., 2009). Public education programs to increase awareness about patient rights and the dilemma of collusion can also be conceived (Low et al., 2009). Moreover, findings support other evidence that despite the shift in the healthcare approach towards patient self-determination, doctors continue to adopt a paternalistic approach towards the care of patients (McGuire et al., 2005). Total collaboration between patients and medical professionals in decisional priority has yet to gain momentum within Asian healthcare culture. Finally, although resources such as ACP have been put in place for patients to express their care preferences and exercise autonomy, the availability of services within the community to uphold these wishes is currently in critical need for improvement. Without an upgrade of these support facilities, patient autonomy will continue to remain beyond the grasp of the typical local health consumer.

### Limitations, future directions, and conclusion

Readers are cautioned that this study is restricted to an examination of the perspectives of Asian healthcare professionals, and it is recommended that future research in this area should focus on the perspectives of Asian patients to understand their views about autonomy and participation in EoL care. This would allow a comprehensive examination of the notion of patient autonomy and patient participation in healthcare at life's concluding moments within the Asian context.

With the above said, the present study is a first-of-its kind project to refine the understanding of the notion of patient autonomy and patients' participation in EoL care within the Asian context. It provides evidence that healthcare practitioners in Asian communities must align themselves with the values and needs of patients and their family and jointly make decisions that are consistent and congruent with the values of patients and their families. Sensitivity towards such cross-cultural practices is key to enhancing ACP awareness, discourse, and acceptability in Asian communities.

**Authors' contributions.** All authors were lead investigators, employed research staff or graduate students, and devoted at least 40% of their time to this study. O.D. took field notes during data collection, coded, analyzed, and interpreted the data, and drafted and revised the article. P.L. conceived and designed the study, co-moderated the FGDs during data collection, coded, analyzed, and interpreted the data, and revised the article. P.V. took field notes during data collection, coded, analyzed, and interpreted the data, and revised the article. J.C., C.K.L., and W.S.T. conceived the study, obtained funding, audited the data, and revised the article. W.S.T. also co-moderated the FGDs during data collection. A.H.Y.H. conceived and designed the study, moderated the FGDs during data collection, coded analyzed and interpreted the data, and revised the article. All authors gave final approval of the revision to be published. A.H.Y.H. is the guarantor.

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