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Cultural influences upon advance care planning in a family-centric society

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ABSTRACT

Objective: Advanced care plans (ACPs) are designed to convey the wishes of patients with regards to their care in the event of incapacity. There are a number of prerequisites for creation of an effective ACP. First, the patient must be aware of their condition, their prognosis, the likely trajectory of the illness, and the potential treatment options available to them. Second, patient input into ACP must be free of any coercive factors. Third, the patient must be able to remain involved in adapting their ACP as their condition evolves. Continued use of familial determination and collusion within the local healthcare system, however, has raised concerns that the basic requirements for effective ACP cannot be met.

Method: To assess the credibility of these concerns, we employed a video vignette approach depicting a family of three adult children discussing whether or not to reveal a cancer diagnosis to their mother. Semistructured interviews with 72 oncology patients and 60 of their caregivers were conducted afterwards to explore the views of the participants on the different positions taken by the children.

Results: Collusion, family-centric decision making, adulteration of information provided to patients, and circumnavigation of patient involvement appear to be context-dependent. Patients and families alike believe that patients should be told of their conditions. However, the incidence of collusion and familial determination increases with determinations of a poor prognosis, a poor anticipated response to chemotherapy, and a poor premorbid health status. Financial considerations with respect to care determinations remain secondary considerations.

Significance of results: Our data suggest that ACPs can be effectively constructed in family-centric societies so long as healthcare professionals continue to update and educate families on the patient's situation. Collusion and familial intervention in the decision-making process are part of efforts to protect the patient from distress and are neither solely dependent on cultural nor an "all-or-nothing" phenomenon. The response of families are context-dependent and patient-specific, weighing the patient's right to know and prepare and the potential distress it is likely to cause. In most cases, the news is broken gently over time to allow the patient to digest the information and for the family to assess how well they cope with the news. Furthermore, the actions of families are dependent upon their understanding of the situation, highlighting the need for continued engagement with healthcare professionals.

KEYWORDS: Advance care planning, End-of-life care, Palliative medicine, Collusion, Familial decision making

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INTRODUCTION

A person's right to "make decisions and direct their life" even when they lack decision-making capacity is underpinned by the principle of autonomy and is preserved within an advanced care plans (ACPs). Russell (2014) defines advance care planning as being "concerned with anticipatory end-of-life conversations, subsequent documentation of wishes and care as well as the right to refuse in advance treatments for self or others (e.g., as a proxy or surrogate decision maker) in anticipation of a future loss of capacity." ACPs are thus patient-specific and context-sensitive (Brinkman-Stoppelenburg et al., 2014; Lovell & Yates, 2014).

To be effective, an ACP must be enacted with full participation of a well-informed and competent patient who is fully aware of their condition, its likely trajectory, their prognosis, and the available treatment options, replete with an effective risk–benefit assessment (Lovell & Yates, 2014). Patients must be able to participate in the decision-making process free of coercive influences and must, while still able, review the wishes stated in the ACP in the event of a change in their circumstances.

Meeting these preconditions within the local end-of-life care setting may be challenging when there is collusion, circumnavigation of direct patient involvement in care determinations, and family members are keen to "protect" patients from "bad news" and from "giving up" as a result of local interpretations of Confucian beliefs (Goh, 2008; Toh, 2011; Krishna, 2011*a*; 2011*b*; Tan et al., 2011). Indeed, it is not uncommon for local Singaporean families to resist patients being told about their diagnosis, their prognosis, and/or the extent of their illness (Goh, 2008; Toh, 2011; Krishna, 2011*a*; 2011b; Tan et al., 2011). These practices compromise the patient's ability to provide meaningful input in the construction of an ACP (Goh 2007; 2008; Ho et al., 2010; Krishna, 2011*a*; 2011*b*; Ho et al., 2012; Krishna et al., 2013; Chong et al., 2013; Foo et al., 2013).

The present study aimed to examine the impact of Confucian-inspired beliefs on end-of-life decision making in Singapore. To better understand the implications of prevailing Confucian beliefs upon care determinations, we will first briefly discuss Confucian practice in Singapore.

DECISION MAKING IN A CONFUCIAN-INSPIRED SOCIETY

As with Japan, China, South Korea, Taiwan, and Hong Kong, Singapore remains influenced by Confucian inspired family-centric beliefs (Cheng, 1986; Fan, 1997; Tsai, 1999; Low et al., 2000; Tsai, 2001; Ong et al., 2002; 2012; Ho, 2004; Teo, 2004; Chan et al., 2006; Fan, 2007; Ho, 2008; Hui, 2008; Low et al., 2009; Wong & Verbrugge, 2009; Ho et al., 2010; Krishna, 2011*a*; 2011*b*; Cheng et al., 2012; Yang et al., 2012; Zhang, 2012). The impact of these beliefs in the context of the present discussion lies primarily in the presence of filial obligations that require the family to show their care and affection for the patient by providing the patient with physical, financial, existential, emotional, and social support (Ho et al., 2012).

Key aspects of meeting these expectations are shielding the patient from any stress and helping them to maintain hope (Goh, 2007; 2008). The prevailing sociocultural beliefs maintain that the presence of stressful and demoralizing factors will shorten life (Goh, 2008; Toh, 2011; Krishna, 2011; Tan et al., 2011). In addition, local cultural mores demand that families maintain their duties of sustaining hope and buffering patients from stress and worries until the patient's death, ostensibly as a sign of non-abandonment and continued care and respect. As a result of literal interpretations of these expectations, discussions about cancer diagnoses, treatment options, changes in approaches to care and the goals of care, end-of-life care decisions, and end-of-life wishes often do not involve the patients (Goh, 2008; Toh, 2011; Krishna, 2011; Tan et al., 2011). Indeed, discussions about death and dying remain taboo within the local setting (Goh, 2008).

Chong et al. (2013) and Phua et al. (2011) found that less than 10% of patients were involved in their end-of-life care discussions. Rather, it was the family that determined the course of care, highlighting the prevalence of familial determination and collusion. So strong is the influence of the family in end-of-life care decisions that Foo et al. (2013) reported that up to 40% of physicians would override the previously stated wishes of a now incompetent patient in favor of the diametrically opposed wishes of the family. Accounts of families employing alternative and unproven treatment options in end-of-life care and sometimes concurrently with established hospital treatments are testimony to the influence of families within the local end-of-life decision-making process (Goh, 2008; Ho et al., 2010; Toh, 2011; Krishna, 2011; Tan et al., 2011).

The presence of collusion, circumnavigation of direct patient involvement in care determinations, and familial determination in tandem with efforts of the family to employ alternative treatment options simply to "delay" discussions about death and dying raise questions about the viability of ACP (Fried et al., 2007*a*; 2007*b*; 2009; Clarke & Seymour, 2010; MacPherson et al., 2013).

STUDY METHODOLOGY

Methodology

To scrutinize the impact of these sociocultural factors and promote overcoming social cultural taboos against discussing death and dying, our research employed a video vignette study (Goh, 2007; 2008; Krishna, 2011*a*; 2011*b*).

The vignette had two parts. The first part of the vignette, lasting nearly 7 minutes, depicts a family of three adult children who stumble upon news that their 72-year-old mother (Mrs. Tan) is being examined for cancer. Each adult child expresses a different view on how to proceed with her treatment. Mrs. Tan's two daughters were keen that Mrs. Tan was not to be told about her diagnosis. They insisted on collusion and exclusion of the patient from the decision-making process in fear of the likely psychological impact on the patient, who had recently lost her spouse to cancer. One of Mrs. Tan's daughter (Wen) was concerned that Mrs. Tan would be unlikely to cope with the news, particularly following the difficult death of her husband from cancer in the previous year. Mrs. Tan's other daughter (Xiang) was concerned about the impact of the cost of any treatment, particularly as her father's treatment had greatly reduced their savings. On the other hand, Mrs. Tan's only son advocated that she be told and that her treatment focus on maximizing Mrs. Tan's quantity of life (QuoL).

After viewing this 7-minute installment of the video vignette, participants had face-to-face audiotaped interviews with trained interviewers. The questions focused on participants' views and the rationale for their positions on whether Mrs. Tan should be told about her diagnosis, how Mrs. Tan might respond should she eventually find out that her diagnosis had been withheld, what the participants themselves would do in such circumstances, and what they felt the physician ought to do in the face of familial resistance to revealing a diagnosis of cancer to the patient.

To elucidate the impact of other common considerations in end-of-life deliberations in Singapore, we provided participants with different scenarios of Mrs. Tan to elicit the impact that age, present clinical condition, prognosis, premorbid state, and financial status would have on the decision-making process.

The video was designed by a panel of local experts and drew upon prevailing local data, feedback from patients, relevant theories, refined key issues that required being addressed, psychological factors, participant characteristics, and cultural/religious factors. The expert panel also helped construct the purposedly designed semistructured study questionnaire.

After completing the interviews, participants viewed the second 7-minute video vignette, designed to examine how each of the children were perceived to have garnered an insight into how QoL advocates are viewed in local society.

We now present the findings with respect to the first part of the video.

Subjects

The participants were patients and their caregivers (as identified by the patient to be the primary care provider) attending the ambulatory treatment unit (ATU) at the National Cancer Centre–Singapore between April of 2014 and June of 2014. Participants accompanied by their caregivers (who were adult family members and identified by the patient to be their primary caregiver) were recruited randomly as they attended the ATU for the patient's chemotherapy. Written informed consent was obtained from both the patient and caregiver prior to participation in the study, which was approved by the SingHealth Centralized Institutional Review Board. The duration of each interview, including watching of the video, lasted between 25 and 40 minutes.

Participants and Eligibility Criteria

Convenience sampling was employed to recruit patients who were over the age of 21 years, had a cancer diagnosis (any stage), and were able to understand English or Mandarin. Primary caregivers over the age of 21 and able to understand English or Mandarin were identified by patients participating in the study and were recruited. Six trained interviewers carried out all audiotaped interviews, which were transcribed verbatim and translated into English, if required.

Coding

The completed transcripts of the audiotaped interviews were labeled with unique numeric identifiers and de-identified. Three members of the investigating team coded the 132 completed transcripts independently.

An iterative review saw participants who asked additional questions regarding the key considerations that patients and caregivers had stated had influenced their decision-making process. As a result, participants were asked whether they would discuss the diagnosis with the patient if the patient were older, had poor premorbid health, had metastatic disease, or had insurance to cover all the costs of treatment.

We employed grounded theory to identify key themes within the transcripts. The absence of an a-priori framework for and a lack of understanding in decision-making processes in Singapore underpinned adoption of a constructivist approach (Kennedy & Lingard, 2006; Creswell, 2003). Charmaz's (2000; 2006; 2009) constructivist concept of grounded theory allows for an understanding of "what influences end-of-life decision-making processes in Singapore" (Creswell, 2003). This approach allowed for the constructed meaning of social experiences within end-of-life decision-making to be derived "through the development of theoretical explanations that are 'grounded' in practical experiences" (Lingard et al., 2008, p. 459; Sbaraini et al., 2011). It also takes into account the influences of our clinical experiences, background, and beliefs in coding and interpreting these data (Charmaz, 2000; 2006; Creswell, 2003). Grounded theory allows for common themes from various individual mentoring accounts to be categorized. An iterative process was also employed to allow "whatever is theoretically relevant to emerge" (Wimpenny & Gass, 2000, p. 1487) and drive future data collection (theoretical sampling) (Baker et al., 1992; Starks & Trinidad, 2007).

Saturation of thematic analysis was attained by the 82nd case, and there were no contradictory data identified in the remaining 50 cases. All members of the team discussed any discordance in the coding, and a majority verdict was applied.

RESULTS

A total of 136 patients and caregivers were interviewed. Four interviews were excluded from data analysis given that they did not proceed beyond collection of demographic data, as they were about to commence treatment, leaving a total of 72 patients and 60 caregivers (Table 1).

We will now present the responses to the four questions and the four variations asked of all participants as well as the key themes drawn in reverse order of importance, as determined by the frequency at which they appeared in the discussions.

Table 1. *Respondent demographics*

Number of participants	132
Male, *n* (%)	48 (36.4)
Female, *n* (%)	84 (63.6)
Age, mean (*SD*)	49.7 (12.5)
Race, *n* (%)	
Chinese	109 (82.6)
Malay	3 (2.3)
Indian	15 (11.4)
Other	5 (3.8)
Education level, *n* (%)	
No formal education	2 (1.5)
Primary	24 (18.2)
Secondary	60 (45.5)
Tertiary	38 (28.8)
Professional qualifications	8 (6.1)
Marital status, *n* (%)	
Single	14 (10.6)
Married	110 (83.3)
Divorced	3 (2.3)
Widowed	5 (3.8)
Housing, *n* (%)	
2/3-room flat	18 (13.6)
4-room flat	82 (62.1)
Private condominium	13 (9.8)
Landed property	15 (11.4)
Other	4 (3.0)

SD = standard deviation.

Should Mrs. Tan Be Told of Her Diagnosis?

Respondents stated overwhelmingly (129 of 132) that the patient ought to be told. All three dissenters were caregivers. We coded for a total of 345 responses from the 129 participants. The main themes identified in these responses are presented in Table 2.

How Might Mrs. Tan Respond Should She Eventually Find Out that Her Children Withheld the Diagnosis from Her?

We coded for 307 spontaneous responses to this question (Table 3).

What Would Respondents Do if They Were One of Mrs. Tan's Children in Such Circumstances?

There were 195 coded responses from all 132 respondents (see Table 4).

What Ought the Physician Do in Such Circumstances When the Family is Against Revealing a Diagnosis of Cancer to the Patient

Some 53 patients and 35 caregivers felt that it was the physician's duty to tell Mrs. Tan about her diagnosis even if it ran contrary to the wishes of the family, while 14 felt that the patient should not be told based on the presumption of a poor prognosis and a poor chance of cure (Table 5). Underpinning the reasoning not to divulge the diagnosis was the belief that "little good" would come from telling the patient when there was little that could be done about it.

All 102 patients and caregivers on both sides of the argument, together with a further 16 patients and caregivers who had initially reported being "unsure" of what the physician should do, felt that the family ought to discuss their concerns with the physicians.

Table 2. *Reasons why the patient should or should not be told about the diagnosis*

	Reasons for choice arranged in reverse order of importance
Patient should be told about the diagnosis: 129 participants (70 patients and 59 caregivers)	Respondents felt that patient "should know" Respondents felt that patient had a "right" to know Respondents felt that she should be told as it was "her body" Respondents felt that the patient would need to "prepare herself" for any eventuality Respondents concerned themselves with setting out a "care plan" Respondents were concerned that not knowing would worsen the patient's condition and increase her worries Respondents were concerned that patient would "die not knowing"
Patient should not be told the diagnosis: 3 participants (1 patient and 2 caregivers)	Respondents were concerned that patient would become more distressed at the news and this would result in her deterioration Respondents felt that the family ought to decide since they "knew the patient best"

* Each respondent gave more than one reason/response.

Variations of Mrs. Tan's Case

All 132 respondents revealed that Mrs. Tan's relatively "young" age, the new diagnosis, the uncertainty over the possibility for chemotherapy, and the hope of cure were key considerations behind their wish to reveal the diagnosis to Mrs. Tan.

To investigate the importance of these factors with regard to the deliberations, we then altered the details of Mrs. Tan's situation. There were 126 participants in this part of the study, and not all respondents took part because they were called away for treatment. None declined to answer any of the questions or withdrew from the study.

Age

When told that Mrs. Tan was in fact 80 years old and enjoyed an active life with little premorbid illnesses or health complaints, 72 (33 patients and 39 caregivers) reported that they would still reveal the diagnosis to the patient.

Most were concerned with notifying the patient "later on" or at an "appropriate time" after the family

Table 3. *Reasons why the patient would be accepting of or feel upset and/or angry about her children withholding her diagnosis from her*

	Reasons for choice arranged in reverse order of importance
Patient would be accepting: 55 respondents (24 caregivers and 31 patients)	Respondents felt that the patient would see that it was done for "a good reason" Respondents felt that the patient would realize that it was done out of concern for her Respondents felt that the patient would understand that this was done to protect her Respondents felt that the patient would know that this was done out of love for her Respondents felt that the patient would see that "hiding the truth from her" was to prevent her from suffering Respondents stated it was to support her Respondents stated it was to prevent depression
Patient would be angry and/or upset: 77 respondents (32 caregivers and 45 patients)	Respondents felt that the patient "would want to know" Respondents felt that the patient would have been "worrying" as she was not told of the diagnosis Respondents felt that the patient would not have been able to "prepare herself" Respondents felt that the patient would feel "cheated" Respondents stated that "it was her body" Respondents felt that withholding the diagnosis from the patient showed a "lack of respect"

* Each respondent gave more than one reason/response.

Table 4. *Reasons why participants would tell or not tell Mrs. Tan about her diagnosis*

	Reasons for choice
Patient should be told about the diagnosis: all 132 participants (72 patients and 60 caregivers)	Respondents felt that patient "wanted know" Respondents felt that patient had a "right" to know Respondents felt that she would find out Respondents felt that the patient would need to "prepare herself" for any eventuality Respondents felt it was the "truth" Respondents felt it would "protect" her Respondents it would help her "prepare"
Patient should not be told the diagnosis: 14 participants (7 patients and 7 caregivers)	Respondents felt that not telling would "protect" the patient from distress

* Each respondent gave more than one reason/response.

had discussed the issue and prepared her for the news. Here information would be broached in stages, with the final extent of disclosure being dependent on how the patient coped with the information.

Frail Premorbid State

When told that Mrs. Tan was frail and suffered from a number of chronic health problems despite being only 60 years old, we found that patients and caregivers tended to be more likely to discuss the diagnosis with the patient. This was primarily because it would allow Mrs. Tan to have the time to "prepare" and also to make an informed decision about her goals of care and treatment options.

Most patients and caregivers felt that they would disclose the diagnosis to Mrs. Tan immediately and in the presence of the physician, as they believed this would allow the patient a chance to ask the questions that they wanted answered.

For those who did believe that there was little reason to "upset" her with the news and would not reveal her diagnosis, the primary reason for this position was the belief that Mrs. Tan was not "well enough" nor "fit" for chemotherapy treatment. The suggestion was that upsetting the patient about a condition she could do little about would not be helpful.

Metastatic Cancer at Diagnosis

When faced with the situation that Mrs. Tan was otherwise healthy and only 60 years old but had metastatic cancer at diagnosis, most patients and caregivers reported a willingness to tell her about the diagnosis. Their primary reason was that Mrs. Tan was "young" and better able to ask questions, cope with the answers, and deliberate about her goals.

There was also a strong sense that Mrs. Tan ought not be told of the diagnosis as it would have little effect on her plan of care and would be likely to upset

Table 5. *Reasons why the physician should or should not tell Mrs. Tan about her diagnosis in the face of familial resistance*

	Reasons for choice
Patient should be told about the diagnosis: 88 participants (53 patients and 35 caregivers)	Respondents felt that the patient "wanted to know" Respondents felt that the patient had a "right" to know Respondents felt that she would find out Respondents felt that the patient would need to "prepare herself" for any eventuality Respondents felt it was the "truth" Respondents felt it would help her "prepare"
Patient should not be told about the diagnosis: 14 participants (7 patients and 7 caregivers)	Respondents felt that not telling would "protect" the patient from distress
Discuss with the family: 128 participants (65 patients and 63 caregivers)	NB: 5 patients and 11 caregivers included in this total had responded "don't know" to the initial question

* Each respondent gave more than one reason/response.

her. The dominant assumption held was that metastatic disease brought with it a poor prognosis and would likely not prolong her life significantly. There was also an overwhelming belief that such information would "upset" her and "demoralize" her, which would hasten her demise.

Financial Considerations

In the original video vignette, Mrs. Tan referred to her family as an "ordinary Singaporean family" who had used up much of their savings treating her husband for cancer only a year earlier. Financial considerations were part of the reason she stated that she was not keen about undergoing chemotherapy.

When told that Mrs. Tan had a comprehensive insurance package that would entirely cover the costs of her treatment, nearly all patients and caregivers reported that they would tell her about her condition. The dominant belief was that this would provide some chance of improved survival and that, given her young age and her prudence in having an insurance policy for just such an eventuality, suggested that she should at least "try" the treatment.

Many saw the chance of treatment as maintaining hope and maximizing her chances. Some felt that she should use the insurance since "she had already paid for it."

DISCUSSION

Our data provide fresh insights into local end-of-life decision-making practices (Goh 2007; 2008; Ho et al., 2010; Krishna, 2011*a*; 2011*b*; Ho et al., 2012; Krishna et al., 2013; Chong et al., 2013; Foo et al., 2013). Scrutiny of our findings revealed that the influence of families in care determinations, the extent of gatekeeping of medical information, and disclosures about clinical conditions by families to patients appeared to be context- and patient-dependent rather then blanket applications of socioculturally influenced practices. Overall, being elderly, having a poor premorbid health status, a poor prognosis, a poor anticipated response to chemotherapy, and metastatic disease would influence respondents to lean toward collusion and family-centric decision-making. Financial considerations did play a part, but the rationale and true impact on decision making need further evaluation.

Our data do reveal five important findings. First, the decision to divulge a clinical diagnosis is defined in part by the family's perceptions and what they understand about the situation rather than blind compliance with sociocultural practices. There is clear evidence that patients and caregivers do balance the overall benefits of discussing a diagnosis with the potential for causing distress, particularly as it was the patient's right to know and prepare for what was to come. It is clear that what the family understands about the patient's status, their conceptions about a cancer diagnosis and its severity at the time of diagnosis, the potential response to chemotherapy, and a meaningful improvement in prognosis are critical factors in their decisions as to whether the patient should be privy to information about their clinical condition.

One significant consideration in deciding not to divulge the diagnosis was the family's awareness of the patient's likely response and the likely impact on their overall care. Indeed the "hopelessness" of the situation may leave families agreeing NOT to tell the patient.

This finding emphasizes that the quality of information being provided to the family is important, as opposed to merely "full disclosure of the facts." Careful attention should be paid to explicate the information and address the concerns that may arise as a result of receiving that information. This is especially so when discussing the trajectory of the illness and the likely compromises to the patient's situation, and the nature and effects of the available treatments, as well as the potential places of care appropriate for the patient at various junctures along the disease trajectory.

Our data also demonstrate that collusion and familial determination are not an all-or-nothing affair. Indeed, collusion and familial determination would appear to be driven by practical reasons, such as a patient's clinical condition, their age, and their present and premorbid conditions, rather than simply abiding by sociocultural beliefs. Patients and caregivers do believe that patients will eventually "find out" about their condition and that, though they may "accept" the rationale for the families' actions, it is likely that these actions will have far worse repercussions for the patient and family. Many accept the fact that the distress caused and the damage to their relationships with other family members are likely to be significant and at least no less upsetting than the original news.

In many cases, patients and caregivers do believe that patients should be told about their diagnosis but simply wish to do it in "stages" or at "the appropriate time." Patients and caregivers are more likely to employ a deferred and stepwise breaking of bad news if the patient has metastatic disease and stage 4 cancer or when the patient is old and has a poor premorbid state. In many cases, this process of "gentle" breaking of bad news will still involve the physician. This emphasizes the importance of regular discussions with the family and the patient as the disease progresses or at points where changes in treatment approaches and direction are evident as families struggle to balance their responsibilities to care for the patient, with their acceptance that in many cases patients have a “right” to know. “Journeying with the patient and family”—a catchphrase in local palliative care circles—becomes all the more important if appropriate care is to be provided to patients and families are to be adequately supported.

It is also clear that practices in Singapore are evolving. Almost ubiquitous application of collusion and familial decision-making appears to be giving way to increasing use of stepwise provision of information and/or provision of adulterated information that in turn evolves depending on how the patient copes with that information. The increasing numbers of advance care plans being created would suggest that this change is occurring and that more patients are being made aware of their diagnosis.

The emphasis now should be upon better appraisal of the needs of the patient and the family, as well as continued communications between the healthcare team and families as situations evolve, the disease progresses, and patient needs change.

LIMITATIONS OF THE STUDY

While our study had a rather large sample size, the conclusions may not be entirely transferable to the general public, given that our sample population were patients who were aware of their diagnosis and who were likely to support patient involvement in care determinations.

There may also be social acceptability bias as participants wanted to be seen as acting in a manner that would be acceptable to the interviewers and the “Western” researchers who would be analyzing the data. So their responses may not reflect their genuine thoughts.

Furthermore, our sample population consisted of cancer patients whose prognosis and treatment outcomes were sometimes more easily predicted than patients with chronic non-cancer life-limiting disorders. Ready access to palliative care teams and the holistic support they provide to patients and their families also promotes end-of-life discussions. Such access is limited in many non-cancer settings and may impede end-of-life discussions, particularly when the disease trajectory is harder to predict.

CONCLUSIONS

Rather than simply proving that ACP within the Singapore setting is viable and can provide meaningful guidance, our data suggest that ACPs serve a much larger and more important role within the local setting. This is primarily a vehicle for initiating end-of-life discussions in a holistic and practical manner as well as a means to continued contact among patients, families, and their health providers. ACP also helps remind physicians and healthcare professionals of the need for continued engagement with patients and their families throughout the illness journey.

Our data emphasize the need for better provision of patient- and family-centered information, which is sensitive to the contextual needs of the patient and family, and highlight the need for regular updates and inclusive discussions among patients, family, and healthcare teams. This would also enhance palliative care support and provision, particularly at the end of life.

Indeed, while discussion has focused on the Singaporean context and has utilized a combination of prevailing clinical data and new information from a very specific patient population, we suspect that many of the lessons learned may be transferable to other clinical settings, and indeed other family-centric societies.

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