Letter to the Editor

Patient-Surrogate Agreement in Advance Care Planning: Who Are the Surrogates and Are They Making the Right Decisions?

Dear Editor,

Surrogate decision-making based on "substituted judgment" is the concept where surrogates choose the treatment the patient would most want to receive when the patient becomes incompetent.[1] The surrogate decision-making process assumes that the surrogate understands the patient's values and beliefs and uses them to derive the patient's end-of-life care preferences. However, studies have shown poor concordance between what individuals would choose in critical medical situations and what proxies would choose for them.[2-4] A review found that proxies could accurately report some aspects of the end-of-life patient's experience, but these reports were subjected to multiple biases.[5] From the observed differences between surrogates' and patients' choices, validity of substituted judgment is in question.

In Singapore, limited evidence on the effectiveness has been found from a few studies[6-8] conducted on advance care planning (ACP), a nationwide initiative that was recommended to be implemented to be a part of standard care. Most studies that have been conducted on patient-surrogate agreement on preferences were done overseas[9-11] and a few focused on end-of-life patients. The purpose of this study is to examine the extent of agreement between end-of-life patients and their surrogates on the patient's preferences in ACP.

Materials and Methods

Setting and Recruitment

In this cross-sectional study, participants consisted of pairs of end-of-life patients and their surrogates recruited from the ACP department of an acute hospital in Singapore. Patients who were assessed to be "not surprised if they die in the next one year" were referred by the primary care team to the ACP department.

The patients were eligible for the study if they were communicative, spoke either English and/or Mandarin Chinese, selected a surrogate for the ACP session, and were at end-of-life. Patients with a history of psychiatric-related illnesses were also excluded. Surrogates were eligible if they were 18 years of age or older and could speak either English or Mandarin Chinese.

Procedure

At 30 minutes before the ACP session, a trained researcher asked the patient-surrogate pair to participate in the study. Both the patient and the surrogate who agreed to enrol in the study gave written informed consent. Demographic data collected from the patient's case record included age, race, and gender while the clinical data included Geriatric Depression Scale (GDS-7) score, Abbreviated Mental Test score, and the Modified Barthel Index (MBI-20) score. These clinical data were collected to understand the patient's state of psychological and physical health at the point of the study.

The surrogate filled in a survey form in a separate room from the patient. The survey included surrogates' sociodemographic status, a rating of how well the surrogate knows the patient, and the patient's wishes on end-of-life care based on their understanding of the patient. The survey took about 20 minutes to answer. During the ACP session, an experienced ACP facilitator would discuss and document the patient's preferences on end-of-life care. The preferences documented during the ACP were then compared to the surrogates' survey responses.

Data Analysis

Descriptive statistics such as frequencies, proportions, and means (standard deviations) were used to characterise the study participants. Medians were used to describe non-parametric data. Agreement between patients and surrogates on the patient's ACP preferences was analysed in contingency tables and characterised using percent agreement and Cohen's kappa coefficient. For the agreement analysis, when statistically significant, an absolute k value between 0.1 and 0.3 was considered as mild agreement; 0.31 to 0.6 as moderate; 0.61 to 0.8 as good; and 0.8 to 1.0 as excellent. To test for statistically significant systematic differences between patient and family choices, the Wilcoxon matched-pairs signed rank test was used.

Results

Participant Characteristics

Thirty patient-surrogate pairs participated in the study between January 2015 to January 2018. Patients were mainly Chinese (70%) and male (60%) (Table 1). Median

Table 1. Characteristics of Patients

	Patient n = 30
Median age (range)	80 (59 – 97)
Gender (%)	
Female	12 (40)
Ethnicity (%)	
Chinese	21 (70)
Malay	5 (16)
Indian	3 (10)
Others	1 (3)
Median Geriatric Depression Scale score (range)	1 (0 – 7)
Median Modified Barthel Index score (range)	12.5 (1 – 20)

age of the patients was 80 (range 59-97) and the median MBI-20 score was 12.5 (range 1-20). The median GDS-7 score was 1 (range 1-7). Surrogates were of the median age of 50 (range 22-73) and 60% of them were children of the patients (Table 2).

The patient and the surrogate choices and the corresponding kappa values on the agreement are shown in Table 3. Higher kappa values indicate better patient-surrogate agreement. We took on a conservative approach for agreement and only considered good to excellent agreement as acceptable in this study. Surrogates had a mean rating of 4.0 (range 3.0-5.0) when asked on a 5-point Likert scale on how well they think they know the patient, with 1 being not well at all and 5 being very well. Twenty (66.7%) surrogates rated "well" and "very well". However, in these patient-surrogate pairs, we did not find good agreement in all the

Table 2. Characteristics of Surrogates

	Surrogate n = 30
Age (range)	50 (22 – 73)
Gender (%)	
Female	17 (57)
Marital status (%)	
Married	21 (70)
Single/divorced	7 (23)
Highest attained education level (%)	
Primary	6 (20)
Secondary	8 (27)
Tertiary	11 (37)
Relationship to patient (%)	
Child	18 (60)
Parent	3 (10)
Spouse	5 (17)
Sibling	1 (3)
Living in same household as patient (%)	18 (60)
Main caregiver for patient (%)	14 (47)

preferences. This reflects inaccuracy in the surrogate's prediction of the patient's choice even if the surrogates perceived that they know the patient well. Of these pairs, only 11 (55%) were the patient's main caregiver and this could explain the inaccuracy.

Kappa values for the extent of agreement on end-of-life care preferences ranged from 0.09 to 0.62 with an average of 0.37, indicating poor to good consistency in preferences. Only 40% of the patient-surrogate pairs agreed that the patient would not want to be attempted cardiopulmonary resuscitation (CPR) during a medical crisis. Cohen's Kappa could not be calculated as 100% of the patients chose the same preference (i.e. do not attempt CPR). Significant differences ($P <0.01$) were found in the patient and surrogate choices in CPR status and hence implied that most surrogates were not able to predict the patient's choice in CPR status.

On the patient's views on type of medical intervention, 56.7% of the patient-surrogate pairs agreed (with majority agreeing on the option "limited trial of intervention" [k = 0.09, 95% CI 0.00-0.46]). Moderate agreement was seen in the patient's and surrogate's reported choices on patient's place of medical intervention (k = 0.40, 95% CI 0.17-0.63). However, differences between the patient and surrogate choices on trial of care and place of medical intervention were insignificant.

Fifty percent of the pairs agreed on the option of place of death and good agreement was observed (k = 0.62, 95% CI 0.45-0.94). Of this, majority of the agreement was on "no preference on the place of death". In summary, of the 4 preferred plans of care preferences, most of the surrogates could only predict accurately the patient's preferred place of death. However, since more than half (57%) of the patients did not have a preference on place of death, they may not view dying in place as important as other end-of-life care preferences.

Discussion

We included end-of-life patients in the study as they are nearing death and more likely to have a better grasp of their end-of-life preferences. In terms of acceptability, exploratory studies in patients with advanced cancer have found ACP discussions acceptable and feasible.[12]

Our findings revealed important patterns in disagreement and implied issues in surrogate decision-making. Surrogates tended to overestimate the patient's preference on CPR status and we postulate that they may hold an unduly high expectation of the efficacy of life-saving interventions. Surrogates' knowledge of CPR—including the indications for and the outcomes of CPR—has been found to be poor. Patients and families believed that the success rate for CPR exceeds 50%[13] although many studies have shown that the likelihood of surviving CPR is near to zero.[14] This advocates

Table 3. Preferences in Advance Care Planning

Preference	Patient n = 30	Surrogate n = 30
1. Options regarding cardiopulmonary resuscitation (%)		
To proceed with CPR, attempt resuscitation	0 (0)	6 (20)
Do not attempt CPR, allow natural death	30 (100)	24 (80)
2. Options regarding medical intervention (%)		
Full treatment	1 (3)	9 (30)
Limited medical intervention	26 (87)	17 (57)
Comfort measures only	3 (10)	4 (13)
3. Options regarding preferred place of medical treatment and care (%)		
Transfer to hospital	9 (30)	9 (30)
Trial or treatment in own home/nursing home/hospice	10 (33)	5 (17)
Remain in my own home	4 (13)	13 (43)
No preference	6 (20)	3 (10)
Others	1 (3)	0 (0)
4. Options regarding preferred place of death (%)		
Hospital	3 (10)	2 (7)
Own home	9 (30)	19 (63)
No preference	17 (57)	9 (30)
Hospice	1 (3)	0 (0)

CPR: Cardiopulmonary resuscitation

Note: Because of rounding, not all percentages total 100.

a need to continue improving substitute decision-making so that patients can be more confident that surrogates can make decisions consistent to their wishes.

This study suggested inadequacy in educating surrogates on their role in the ACP process. While it is recognised that an important outcome of ACP is to improve surrogates' knowledge of patients' illness, prognosis and the corresponding life-saving/comfort care procedures, few studies were conducted to measure knowledge. Further research should work on developing an instrument to measure patients' and surrogates' knowledge at pre- and post-ACP. Further research should also look into social factors related to discordances and roles of other surrogates (e.g. clinical personnel, family members and caregivers) in the medical encounter.

Difficulty in recruiting participants for this study limited its sample size. Surrogates refused participation due to the concern that the study may cause a burden to the patient. Due to the high refusal rate, self-selection bias is a concern in this study. The findings cannot be generalised as they come from a non-representative, local sample of patients and surrogates.

Conclusion

Surrogates' understanding of patient preferences are often inaccurate, likely a result of inadequate knowledge that arose from lack of surrogate education during an ACP.

Further research would be to measure ACP's effectiveness in improving surrogates' knowledge on their role, patient's illness and life-saving/comfort care procedures.

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