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A cross-sectional profile of real-life decisions about end-of-life care preferences in a Southeast Asian country

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ABSTRACT

Objective To describe the end-of-life care preferences of individuals who have formally completed their advance care plans (ACP), and to examine the influence of age and gender on these preferences.

Design, setting, and participants A cross-sectional study was conducted to profile the end-of-life care preferences. Participants included all adults (≥ 21 years old) (n=3,380) who had completed a statement of their preferences as part of a national ACP programme in Singapore. The study timeframe was between January 2011 and December 2015.

Main Measures End-of-life care preferences were obtained from the ACP document. The extent of decisions differed based on one's health status (healthy, chronically ill, or diagnosed with advanced illnesses). To analyse the data, descriptive statistics and logistic regression analysis were used.

Results The median time between ACP documentation and death was 7.3 months (95% Confidence Interval: 6.35-8. Immediate family members formed the majority of nominated substitute decision makers. 18). Across healthy, and chronically ill patients, the majority did not opt for cardiopulmonary resuscitation (CPR) or other life-sustaining measures. Among individuals with advanced illnesses, 94% preferred not to attempt CPR but 69% still preferred to receive some form of active medical treatment. Approximately 40% chose to be cared for, and to die at home. We found that the preferred place of care is related to but not synonymous with the place of death. Age and sex significantly predict preferences in those with advanced illnesses.

Conclusion This study presented a comprehensive overview of end-of-life care preferences in this Singaporean sample. Most individuals preferred to not proceed with life-sustaining treatments. However, among those with advanced illnesses, there was still a strong preference to receive some form of limited treatment. Better understanding of end-of-life care preferences through ACP can better guide end-of-life care programme planning, and resource allocation decisions.

Keywords advance care planning; patient preferences; place of care; place of death; cross sectional studies

ARTICLE SUMMARY

Strengths and limitations of this study

- Large sample size that spanned across seven acute care hospitals, and twelve different social care providers in Singapore.
- Profiled the demographics and end-of-life care preferences decided under real-life situations

- Amongst individuals diagnosed with advance illnesses, this study examined the relationship between preferences for place of care and place of death
- Amongst individuals diagnosed with advance illnesses, this study examined the association between end-of-life care preferences and age as well as sex
- Most the ACPs were conducted in acute care settings, and the results may not be generalisable to other populations.

INTRODUCTION

Most societies with a rapidly ageing population would encounter challenges in providing high quality end-of-life care. In many jurisdictions, an individual could designate a health care decision-maker, and specify decisions regarding life-sustaining treatments in the event of decisional incapacitation, in a legally binding advance directive (AD). In 1991, the Patient Self-Determination Act (PSDA) was enacted in the US, by requiring healthcare institutions to provide information to adult patients about advance health care directives, upon admission to a healthcare facility (1). Since then, other countries have joined the movement to empower patients by introducing legislation.

In 1996, the Advance Medical Directive Act was passed in Singapore to safeguard individuals' treatment preferences to forgo extraordinary life-sustaining treatment (2). An individual can opt to sign an advance medical directive to indicate to one's doctor about his/her wishes with regards to the use of life-sustaining treatment in the event of terminal illness and impending death. Out of the 3.9 million resident population (3), only 24,682 individuals have completed an AD between 1997 and 2015, of which only ten were effected (4). International research has cited legal formalities (5, 6) and low public awareness (7) as impediments towards the completion of advance (medical) directives (8, 9).

Due to the shortcomings of setting limits on medical care based on legal means (5), there has been a shift in policy focus towards supporting ongoing communications about end-of-life preferences between involved parties (6) in inpatient, as well as outpatient and community settings (1, 5). Effective communication has been identified as key in improving surrogate accuracy regarding end-of-life care (10), and increasing the level of concordance between received and preferred care (11). By promoting discussions between patients, their loved ones and healthcare professionals, advance care planning (ACP) is thought to better support communication and to align services received by the individuals, with their objectives of their care and their personal preferences (12) (12)

Research has found ACP to empower patients with a greater peace of mind (13), improve the level of agreement with regards to end-of-life care between patient and surrogate, reduce decisional conflict (14) and improve their satisfaction with care (15). The likelihood of dying at their preferred place was also higher among individuals who had completed an ACP (16); the transition between acute and terminal care is often smoother (17) with earlier referrals to community-based palliative care. ACP was associated with avoiding or reducing unnecessary life-sustaining treatments (13, 16), increasing the incidence of out-of-hospital and out-of-intensive care, and increasing the probability of dying at home (18-21).

With this perspective, the Singapore government launched a comprehensive national ACP programme, “Living Matters”, in 2011. “Living Matters” is based on the Respecting Choices® programme at the Gunderson Health System in Wisconsin, US Primarily, the programme aims to systematise the elicitation and documentation of medical and care preferences (22); with a longer-term goal of normalising death and dying conversations in the community (23, 24). Listed amongst populations that are ageing most rapidly in the world, this is a timely effort, as the need to cater for health care, including end-of-life care of the population, is expected to intensify alongside the doubling of the elderly population (25). The ACP programme was launched under the leadership of the Agency for Integrated Care, an independent corporate entity under the purview of the MOH Holdings. In the first phase of the programme implementation, ACP was initiated in public acute care hospitals and specialist care centres. In 2017, AIC shifted the programme towards a public health stance by expanding the outreach and facilitation services to the community (24).

Research has been conducted locally to profile the end-of-life care preferences across different patients and community-based samples (26-29) . The data reported in these studies contained the individual responses of their attitudes and preferences, which may not accurately represent real-world decision-making when families or loved ones are also involved. Therefore, in this article, we review the demographics and end-of-life care preferences, as documented in an Advance Care Plan. Given that end-of-life care preferences could differ across different health states and over one’s life cycle (30), preferences are profiled according to their health status. Additionally, we also examined the effect of age and gender on stated preferences.

METHODOLOGY

Advance Care Planning programme

Similar to Respecting Choices®, "Living Matters" comprised three integrated components: (1) provision of patient educational materials; (2) trained and certified ACP facilitators who assist individuals with ACP; (3) development of an IT system to enable easily storage, and retrieval of ACP forms (31, 32). The programme has adopted a staged approach that considers a person's state of health and allows ACP to be conducted in phases across one's life-time. The conversations can then be individualised based on one's health status, which is broadly categorised as healthy, diagnosed with complex chronic illnesses or diagnosed with advanced illnesses.

Currently, referral to ACP is largely based on clinical judgement and the individual patient's readiness to discuss end-of-life care issues. In practice, a social care or health care professional may facilitate a conversation between the patient, and his/her family members to explore his/her values, beliefs and how this impacts preferences towards medical care at the end-of-life. ACP is not legally binding in Singapore and therefore, there is no need to engage a lawyer for its discussion or documentation (33). All participating patients are encouraged to identify a substitute decision-maker (SDM), who can make health care decisions on their behalf in the event of incapacitation. Different questions and standardised forms apply to each of the three health states (healthy, chronically ill, with advanced illness). End-of-life care preferences are documented in an

IT system after obtaining the patient's concurrence that they accurately reflect their decisions. These recorded preferences are accessible to different providers across the acute care continuum.

Study design and population

This is a cross-sectional study that included all individuals aged 21 years and above, who have completed their ACP between January 2011 and December 2015 across all participating acute care hospitals, specialist care centres, and social care providers in Singapore.

Ethics approval was obtained from the institutional review board of Nanyang Technological University and Domain Specific Review Board of the National Healthcare Group, Singapore. As this is a retrospective database study, written informed consent was waived by both boards.

Elicited preferences by health status

For healthy adults, they were asked about their preferences related to the goals of care when the probability of recovery or survival is low. The choices provided were: "make comfort the goal of my care and do not prolong my life in this condition" or "continue to provide all necessary life-sustaining treatment until outcomes happen to me which I find unacceptable".

For individuals with chronic conditions, the wishes documented in an ACP form specifies preferences about CPR during cardiac arrest, and decisions about treatment options if they were to develop serious complications with (i) a low likelihood of survival, or (ii) a high likelihood of survival but might become immobile and unable to communicate, or (iii) a high likelihood of survival but might suffer from permanent cognitive impairment. The choice categories include “all treatment I need to live as long as I can”, “stop all efforts to keep me alive, allow natural death to happen” and “unsure”.

For individuals with advanced illnesses, they were asked about their CPR preferences, decisions related to medical intervention (comfort, limited additional interventions, full treatment), place of care, and place of death. Under the current programme, full treatment considers intubation, mechanical ventilation, and cardioversion. Medical management may also include transfer to intensive care if indicated. Limited additional interventions include comfort measures and may also include oral or intravenous medications. While non-invasive ventilation support is acceptable, endotracheal intubation or long-term life support measures, including admission to intensive care units are not. Comfort measures include reasonable measures made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort, but it does not include intubation.

For place of medical treatment or care, individuals could opt for the home, hospice, nursing home, hospital, a trial of treatment in their homes before considering transfer to a hospital or a hospice, and a trial of treatment in the hospice or nursing home before transfer to a hospital. The documentation also allowed the individual to indicate “no preferences” and “others”. For place of death, individuals are asked where they would wish to be if they were left with 2-3 days of life. They could opt for either the home, hospital, hospice or nursing home, and two or more alternatives such as home or hospital, and home or nursing home or hospital.

Measures and data extraction

We extracted data on ACP participant profiles and preferences from the national ACP IT system, and the Tan Tock Seng Hospital ACP database. There were three different forms, general, disease specific, and the preferred plan of care (PPC) form, to cater to individuals at different health stages (healthy, chronically ill, advanced illness). Data fields related to the nomination of a substitute decision maker(s), preference about the administration of CPR in the event of a cardiac arrest, and end-of-life care preferences were extracted. In addition, for patients diagnosed with advanced illnesses, we extracted their preferences for place of care and death as well.

To ascertain whether the individuals were deceased, the data was linked to death-related data from the National Registry of Birth and Deaths. Every Singaporean resident is issued with a NRIC number. For this study, a project unique identifying number (PUIN) was generated for each NRIC by a third-party vendor, who was not involved in the analysis of the data. The PUIN was then used to link data belonging to each individual person across the datasets.

Data analysis

Descriptive statistics were used to characterise the sample and to summarise the data related to end-of-life care preferences. To examine the independent effects of age and gender on end-of-life care preferences, logistic regression models were used. All statistical tests were conducted using Stata version 12 (34).

RESULTS

A total of 3,380 completed ACP documents were captured in the databases, with approximately 90% completed in acute hospitals. The patient characteristics can be seen in Table 1. 60% of the patients were aged 75 years and above, and there was demographic variation across the three types of ACP, with younger age profiles for those who completed the general and disease-specific forms. Among all individuals who completed the ACP, 53.2% (1798/3380) were deceased as at 31 December 2015, with the highest share for PPC. The overall median time between ACP completion and death was 7.27 months (95% CI: 6.35-8.18); 63.2% completed ACP within three months prior to death, 52.9% within six months and 42.3% within 12 months.

Table 1 Profile of individuals by type of ACP.

Variable		General	Disease specific	Preferred plan of care	**Total**
Age	< 55 years	77 (11.9)	6 (12.2)	142 (5.3)	225 (6.7)
	55–64 years	193 (29.9)	14 (28.6)	259 (9.6)	466 (13.8)
	65–74 years	203 (31.4)	17 (34.7)	445 (16.6)	665 (19.7)
	≥ 75 years	173 (26.8)	12 (25.5)	1,839 (68.5)	2,024 (59.9)
Sex	Female	359 (55.6)	19 (38.8)	1,316 (49.0)	1,694 (50.1)
	Male	265 (41.0)	28 (57.1)	1,335 (49.7)	1,628 (48.2)
	Missing	22 (3.4)	2 (4.1)	34 (1.3)	58 (1.7)
Deceased		57 (8.8)	10 (20.4)	1,731 (64.5)	1,798 (53.2)
Total		**646 100.0)**	**49 (100.0)**	**2,685 (100.0)**	**3,380 (100.0)**

Documented preferences

Data related to preferences for end-of-life care are represented in Table 2. For healthy individuals who had completed the general ACP, 1 in 8 persons indicated a preference for life-sustaining treatment. For individuals who had completed the disease-specific form, close to 1 in 3 opted for CPR and life-sustaining treatment, even if the likelihood of surviving the complications of the illness were low or if they were to lose their ability to move around or communicate. However, only 16.3% opted for full treatment if they were to become mentally incapacitated because of their illness.

For individuals with advanced illnesses (Table 3), 5.7% opted for CPR and 5.1% opted for full medical intervention. The majority preferred the initiation of a limited trial of treatment, which would be continued with comfort measures if there was no clinical improvement. Approximately 43.6% of individuals preferred to receive treatment in their homes, but 77.4% of these individuals would consider being transferred to an acute hospital after a trial of care at home. Only 29.7% stated the hospital as their preferred site of care. For place of death, 40.4% preferred dying at home, and only 14.1% preferred the hospital. One highlight is that although only 4.1% did not state any preference or were unsure about the place of care, 23.0% of respondents did indicate their preferences with regards to the preferred place of death.

Table 2 End-of-life care preferences in general and disease specific ACP forms.

Documented preferences	**N, %**
General ACP (n = 646)	
Appointment substitute decision maker	581 (89.9)
Comfort measures	560 (86.7)
Life-sustaining treatments	79 (12.2)
Disease specific ACP (n = 49)	
Appointment 1st substitute decision maker	35 (71.4)
Appointment 2nd substitute decision maker	15 (30.6)

Documented preferences	**N, %**
Serious complication with low chance of survival	
Full treatment	16 (32.7)
Stop treatment	31 (63.3)
Serious complication with loss of ability to move around or communicate	
Full treatment	15 (30.6)
Stop treatment	32 (65.3)
Serious complication with mental incapacity	
Full treatment	8 (16.3)
Stop treatment	38 (77.6)
Cardiopulmonary resuscitation	
Attempt	14 (28.6)
Do not attempt	19 (38.8)
Do not attempt if doctor believes low survival chances	14 (28.6)
Preferred plan of care (n = 2685)	
Appointment 1st substitute decision maker	2,526 (94.1)
Appointment 2nd substitute decision maker	1,357 (50.5)
Cardiopulmonary resuscitation	
Attempt	152 (5.7)
Do not attempt	2,511 (93.5)
Do not attempt if doctor believes low survival chances	22 (0.8)
Medical intervention	
Full treatment	138 (5.1)
Limited additional interventions	1,851 (68.9)
Comfort measures only	677 (25.2)
Unsure	19 (0.7)
Preferred place of medical treatment	
Home	265 (9.8)
Hospital	798 (29.7)
Nursing home	166 (6.2)
Hospice	131 (4.9)
Trial of treatment before consider transfer to hospital	
Home	908 (33.8)
Nursing home	269 (10.0)
Hospice	28 (1.0)
Others (no preference, unsure)	110 (4.1)
Missing	10 (0.4)
Preferred place of death	
Patient's home	1,084 (40.4)
Hospital	379 (14.1)
Nursing home	160 (5.9)
Hospice	156 (5.8)
Home or hospital/nursing home/hospice	112 (4.2)
Healthcare institution (hospital or nursing home or hospice)	177 (6.7)
Others (no preference, unsure)	617 (23.0)

ACP: Advance Care Planning; CPR: Cardiopulmonary Resuscitation

Relationship between patient and SDM

The share of individuals who had appointed a substitute decision-maker varied across the three types of ACP. The rates of nomination were, however, lower for those who completed the general and disease-specific plans. For the PPC, only 8% of individuals did not identify a substitute decision-maker (Table 3). From Table 4.4, 78% of individuals nominated their immediate family (spouse, children, grandchildren) to speak on their behalf if they were incapacitated. Only a small percentage nominated non-related persons. Most ACP discussions also took place in the acute care setting.

Table 3 Relationship with substitute decision maker.

	General	Disease specific	Preferred plan of care	Total
Spouse	185 (28.6)	8 (16.3)	320 (11.9)	513 (15.2)
Child, child-in-law, or grandchild	230 (35.6)	20 (40.8)	1869 (69.6)	2119 (62.7)
Other relatives and friends	136 (21.1)	2 (4.1)	266 (9.9)	404 (12.0)
Others (including healthcare professionals)	14 (2.2)	1 (2.0)	10 (0.4)	25 (0.7)
Missing	81 (12.5)	18 (36.7)	220 (8.2)	319 (9.4)
Total	**646 (100.0)**	**49 (100.0)**	**2685 (100.0)**	**3380 (100.0)**

Relationship between preferred place of care and place of death

Table 4 assessed the relationship between place of care and place of death. The results indicated that there was a high level of agreement in preferences related to being cared for at home and dying at home. Other than this, the place of care is not synonymous with where they would like to die at. Close to 1 in 3 individuals who preferred the hospital as the location of care, had also opted for home as the place of death.

Table 4 Preferred place of care and preferred place of death.

Place of Death	Place of Care							
	Home	Hospital	Hospice	Nursing home	Home to Hospital/ Hospice	Hospice to NH/Hospital	Others*	Total
Home	90.9	31.1	9.9	5.4	57.3	12.1	12.7	40.4
Hospital	0.8	30.3	0.0	1.2	9.7	13.7	2.7	14.1
Hospice	0.8	3.1	67.9	0.6	2.6	3.3	4.5	5.8
Nursing home	0.4	0.4	0.0	70.5	0.2	12.1	0.0	6.0
Home or hospital/Nursing home/hospice	1.9	3.5	1.5	0.0	8.0	2.0	2.7	4.4
Healthcare institution	0.4	4.4	4.6	6.6	1.2	30.3	19.1	6.6
Others*	4.9	26.7	16.0	15.7	20.9	26.7	58.2	22.7

*no preferences; unsure

Relationship between treatment preferences and patient profile

As age and sex were not correlated with preferences for healthy and chronically ill individuals, the results were excluded. Table 5 illustrates the results from a logistic regression to assess the impact of age and sex on the preferences of those with advanced illnesses. Those aged 75 years and above were more likely to not opt for CPR and comfort measures, compared to younger individuals. Care at home or having a trial of care at home was the preferred option for the older age group. Similarly, older people exhibited a stronger likelihood of preferring to die at home. There were no significant gender differences in preferences for CPR. However, there was a higher likelihood of females opting for full treatment than comfort measures. This is also consistent with the relatively lower odds of choosing home as the site of care and place of death, compared to males.

Table 5 Multivariable logistic regression of preferences by age and sex with 2,685 subjects who had completed the PPC form.

Preferred plan of care	Age ≥75 vs. Age <75	Female vs. Male
	Adjusted OR (95% CI)	Adjusted OR (95% CI)
CPR		
Attempt vs. Do not attempt	0.31 (018-0.54)	1.56 (0.87-2.79)
Medical intervention		
Treatment vs. Comfort measures	0.32 (0.17-0.62)	2.35 (1.18-4.68)
Preferred place of medical treatment		
Home & trial at home vs. Others	1.52 (1.23-1.89)	0.69 (0.57-0.84)
Preferred place of death		
Home vs. Others	1.29 (1.03-1.61)	0.70 (0.57-0.85)

Model includes variables: age and sex
CPR: Cardiopulmonary Resuscitation; OR: Odds Ratio; C.I.: Confidence Interval

DISCUSSION

This is the first study to profile the end-of-life care preferences amongst individuals who had completed their advance care plan as part of the national ACP programme. ACP is, therefore, an important channel that supports the expression of one's preferences, and to minimise care that is not wished for.

In our study, most individuals nominated their family members to speak on their behalf if they were incapacitated, which is similar to what was observed in other studies (35). Among healthy and chronically ill patients, the majority did not opt for CPR or other life-sustaining measures. Among those with advanced illness, more than 90% preferred not to attempt CPR, but more than 70% still preferred to receive some form of active medical treatment at the end-of-life, rather than comfort care. In this national sample, approximately 4 in 10 chose to be cared for and to die at home. Other Singaporean studies examined the preferences of nursing home residents (36) and those who received care in a day care centre (28). These studies similarly found that while most individuals did not opt for CPR, they did express a preference to receive some form of active treatment (28, 36).

In 2014, the Lien Foundation, a Singapore philanthropic house, commissioned a community-based survey to determine the death attitudes and the level of awareness about hospice and palliative care. The survey reported that 70% and 77% of the surveyed individuals would prefer to be cared for, and to die at home respectively (29). Preferences for medical treatment at home, and for home deaths were significantly lower in our sample. Public opinions often do not coincide with the views of individuals who are close to the end-of-life (37). The complexity of choices grows as death draws near (38) when the individual or their families need to trade-off the place of death against other priorities, such as pain and symptom management, and the physical, emotional and financial burden that death at home may bring (39).

We also found that, although the preferred place of care and place of death are related, they are not equivalent. While only a small percentage of individuals did not have strict preferences about where they are being cared for, almost 1 in 4 individuals expressed that they had no preferred place of death. Other studies have similarly indicated that these two dimensions are not equivalent, although healthcare professionals may use them interchangeably in practice (40).

In our study, the time between ACP completion and death was 7.3 months. While there is no objective optimal timing (41), this is relatively shorter than the median times (14 - 37 months) reported in literature (42, 43). Given that the discussion about preferences should occur before physical or mental incapacitation, earlier initiation can be beneficial to the patients. At the same time, it is important to strike a balance because conducting the ACP conversation too early when preferences are still unstable (44) could lead to unrealistic choices based on hypothesised scenarios (42). ACP initiation should take into account patient and family receptivity, and ideally, precede major health deterioration that could lead to decisional incapacitation (45). Different diseases have different pathways of functional declines (46), which also needs to be considered.

In our sample of patients with advanced illnesses, we found that age was positively associated with preferences to withhold life-sustaining treatments, which was similar to the findings of several studies (47, 48). We found that individuals older than 75 years were more likely to opt for the home as the place of care and death; but other studies reported that younger individuals more strongly prefer home as the place of care (49), or that age did not have a significant effect (50). Cultural differences, in the meaning assigned to the "home" as a place of care and death, or even the availability of alternative palliative care facilities in different countries, could have resulted in the mixed evidence. For instance, due to the availability of inpatient palliative care units in Japan, older individuals had stronger preferences for the patient palliative care unit as the site of care than home (49). Our finding, that females were less likely to prefer to be cared for and die at home, was similarly reported in other studies (51, 52). This could reflect the general longer life expectancy of females compared to males. This reduced likelihood of spousal support at the end-of-life could make home less preferred as an option (53).

Policy & practice implications

Currently, efforts to implement ACP are focused on the elderly and those with advanced illnesses. Based on the numbers of completed disease-specific forms, the take-up by chronically ill individuals is very low. While better integration of ACP with chronic disease management efforts or more rapid expansion of ACP to the outpatient and community settings could assist in improving coverage, additional resources would concurrently be needed to assist hospitals to expand coverage to younger adults, and brining ACP conversations forward in the life-cycle of an individual. Building community awareness of, and acceptance towards ACP will be crucial.

Policies should also consider a range of perspectives and preferences, especially of sub-populations that they will most immediately affect. Preferences elicited from surveys can be viewed as an aspirational target that is achievable if practical barriers were eradicated. Additionally, due to the relatively high proportion of individuals who still preferred hospital as the location of care, policy-makers still need to focus on improving the end-of-life care experience in formal healthcare institutions, while also expanding home palliative care capacity to cater to those who preferred home as the first place of care, and place of death.

Limitations

The sample comprised largely the patients receiving care in the acute care hospitals, and the results may not be generalisable for patients in the community care settings or to other individuals who have elected not to participate in ACP. Individuals who had completed the ACP documentation could be less death-avoidant, and therefore, have different preferences compared to others. Also, as data on ethnic groups and religions were largely absent, these were not reported in this manuscript.

CONCLUSION

This study identified that most of the individuals in our sample, regardless of health status, preferred not to proceed with life-sustaining treatments across a spectrum of health scenarios. However, individuals with advanced illnesses still preferred to receive some form of active support, e.g. non-invasive ventilation support; or oral and intravenous drug administration. Our results imply that policies should consider not just home-based end-of-life care, but also actively focus on the quality of end-of-life care in hospitals, since many individuals still opt for them as the site of care.

ETHICS AND DISSEMINATION

Ethics approval was obtained from the institutional review boards of Nanyang Technological University [Ref: IRB-2016-03-010] and the National Healthcare Group's Domain Specific Review Board [Ref: 2016/00739].

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DATA ACCESS

The data that support the findings of this study are available from the Ministry of Health, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available.

AUTHOR CONTRIBUTION

Woan Shin Tan, and Bajpai Ram conceived and designed the study, obtained, analysed, interpreted the data, drafted and revised the article. Chan Kee Low, Andy Hau Yan Ho and Josip Car conceived the study, obtained funding, audited the data, and revised the article. All authors give final approval of the revision to be published.

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COMPETING INTERESTS

The authors declare no conflict of interest with respect to the research, authorship and/or publication of this article.

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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	8
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-9
Bias	9	Describe any efforts to address potential sources of bias	19-20
Study size	10	Explain how the study size was arrived at	8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10
		(*b*) Describe any methods used to examine subgroups and interactions	10
		(*c*) Explain how missing data were addressed	12-13
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N.A.
		(*e*) Describe any sensitivity analyses	N.A.
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for	12-13

		eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	N.A.
		(c) Consider use of a flow diagram	N.A.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	12-13
Outcome data	15*	Report numbers of outcome events or summary measures	12-13
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	16
		(*b*) Report category boundaries when continuous variables were categorized	16
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N.A.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	13-16
Discussion			
Key results	18	Summarise key results with reference to study objectives	16-18
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	16-20
Generalisability	21	Discuss the generalisability (external validity) of the study results	19-20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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A retrospective cohort analysis of real-life decisions about end-of-life care preferences in a Southeast Asian country

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ABSTRACT

Objective To describe the end-of-life care preferences of individuals, and to examine the influence of age and gender on these preferences.

Design, setting, and participants A retrospective cohort study was conducted. Participants included all adults (≥ 21 years old) (n=3,380) who had completed a statement of their preferences as part of a national ACP programme in Singapore. Data were extracted from the national and Tan Tock Seng Hospital ACP database.

Main Measures End-of-life care preferences were obtained from the ACP document and differentiated by health status (healthy, chronically ill, or diagnosed with advanced illnesses). To analyse the data, descriptive statistics and logistic regression analysis were used.

Results Across healthy, and chronically ill patients, the majority did not opt for cardiopulmonary resuscitation (CPR) or other life-sustaining measures. Among individuals with advanced illnesses, 94% preferred not to attempt CPR but 69% still preferred to receive some form of active medical treatment. Approximately 40% chose to be cared for, and to die at home. Age and sex significantly predict preferences in those with advanced illnesses. Older age (>=75 years) showed higher odds for home as preferred place of care (odds ratio (OR): 1.52; 95% CI: 1.23-1.89) and place of death (OR: 1.29; 95%CI: 1.03-1.61) and lower odds for CPR (OR: 0.31; 95%CI: 0.18-0.54) and full treatment (OR: 0.32; 95% CI: 0.17-0.62). Being female was associated with lower odds for home as preferred place of care (OR): 0.69; 95% CI: 0.57-0.84) and place of death (OR: 0.70; 95% CI: 0.57-0.85) and higher odds for full treatment (OR: 2.35; 95% CI: 1.18-4.68).

Conclusion The majority preferred to not proceed with life-sustaining treatments, but there was still a strong preference to receive some form of limited treatment. Better understanding of end-of-life care preferences through ACP can better guide end-of-life care programme planning, and resource allocation decisions.

ARTICLE SUMMARY

Strengths and limitations of this study

- Examined real-life end-of-life preferences of individuals across different health states
- Comprehensive coverage of a large sample of patients who received care from seven acute care hospitals, and twelve different social care providers in Singapore
- Examined the association of end-of-life care preferences with age and sex but was unable to examine the correlation with other covariates due to data limitation
- Individuals who voluntarily completed their advance care plans could be less death-avoidant
- Prospective study will allow for gathering of more variables that influence end-of-life care preferences which this study lacks

INTRODUCTION

Most societies that are experiencing a rapidly ageing population would encounter challenges in providing high quality end-of-life care to its population. In many jurisdictions, through a process of Advance Care Planning (ACP) an individual could designate a health care decision-maker, and specify decisions regarding life-sustaining treatments in the event of decisional incapacitation. Research has found ACP to empower patients with a greater peace of mind (1), improve the level of agreement with regards to end-of-life care between patient and surrogate, reduce decisional conflict (2) and improve their satisfaction with care (3). The likelihood of dying at their preferred place was also higher among individuals who had completed an ACP (4); the transition between acute and terminal care is often smoother (5). ACP was also associated with avoiding or reducing unnecessary life-sustaining treatments (1, 4), increasing the incidence of out-of-hospital and out-of-intensive care, and increasing the probability of dying at home (6-9).

With this perspective, the Singapore government launched a comprehensive national ACP programme, “Living Matters”, in 2011. “Living Matters” is based on the Respecting Choices® programme at the Gundersen Health System in Wisconsin, US. Primarily, the programme aims to systematise the elicitation and documentation of medical and care preferences (10); with a longer-term goal of normalising death and dying conversations in the community (11, 12). Listed amongst populations that are ageing most rapidly in the world, this is a timely effort, as the need to cater for health care, including end-of-life care of the population, is expected to intensify alongside the doubling of the elderly population (13).

Surveys have been conducted locally to profile the end-of-life care preferences across different patients and community-based samples (14-17). However, surveys often require individuals to respond to a single question about their preferred place of death, based on a hypothetical end-of-life scenario (18) without having to trade-off against other priorities or account for other than one's personal concerns. Therefore, choices elicited through a survey could reflect what is preferred under more "ideal" circumstances. Since an illness impacts the individual biologically as well as socially (19), the survey process may not mirror real-life decision-making processes well (20).

Therefore, in this article, we review the demographics and end-of-life care preferences, as documented in an Advance Care Plan. Given that end-of-life care preferences could differ across different health states and over one's life cycle (21), preferences are profiled according to their health status. Additionally, we also examined the effect of age and gender on stated preferences.

METHODOLOGY

Advance Care Planning programme

The "Living Matters" programme comprised three integrated components: (1) provision of patient educational materials; (2) trained and certified ACP facilitators who assist individuals with ACP; (3) development of an IT system to enable easily storage, and retrieval of ACP forms (22, 23). The programme has adopted a staged approach that considers a person's state of health and allows ACP to be conducted in phases across one's life-time. The conversations can then be individualised based on one's health status, which is broadly categorised as healthy, diagnosed with complex chronic illnesses or diagnosed with advanced illnesses.

Currently, referral to ACP and the staging of one's health status is largely based on clinical judgement. Individual clinicians also assess the individual patient's readiness to discuss end-of-life care issues. In practice, a social care or health care professional may facilitate a conversation between the patient, and his/her family members to explore his/her values, beliefs and how this impacts preferences towards medical care at the end-of-life. ACP is not legally binding in Singapore and therefore, there is no need to engage a lawyer for its discussion or documentation (24). All participating patients are encouraged to identify a substitute decision-maker (SDM), who can make health care decisions on their behalf in the event of incapacitation.

Different questions and standardised forms apply to each of the three health states (healthy, chronically ill, with advanced illness) (Figure 1). Individuals identify a substitute decision-maker and also establish the goals of care relevant to their disease stage. They are intended to update their decisions as they transit health states. For instance, questions regarding disease-related complications are not applicable to a healthy individual whereas, for an individual with a poor prognosis, questions related to disease-related complications may no longer be applicable. Rather, they may be concerned about care during the terminal phase.

End-of-life care preferences are documented in an IT system after obtaining the patient's concurrence that they accurately reflect their decisions. These recorded preferences are accessible to different providers across the acute care continuum.

Study design and population

This is a retrospective cohort study that included all individuals aged 21 years and above, who have completed their ACP between January 2011 and December 2015 across all participating acute care hospitals, specialist care centres, and social care providers in Singapore.

Patient and public involvement

Patients were not involved in the design of the study although end-of-life care preferences documented as part of routine clinical care were aggregated and reported in this study. As only anonymised data were analysed, data were not disseminated to the patients.

Ethics and consent

Ethics approval was obtained from the institutional review board of Nanyang Technological University and Domain Specific Review Board of the National Healthcare Group, Singapore. As this is a retrospective database study, written informed consent was waived by both boards.

Elicited preferences by health status

There were three different forms, general, disease specific, and the preferred plan of care (PPC) form, to cater to individuals at different health stages (healthy, chronically ill, advanced illness).

For healthy adults, they were asked about their preferences related to the goals of care when the probability of recovery or survival is low. The choices provided were: "make comfort the goal of my care and do not prolong my life in this condition" or "continue to provide all necessary life-sustaining treatment until outcomes happen to me which I find unacceptable".

For individuals with chronic conditions, the wishes documented in an ACP form specifies preferences about CPR during cardiac arrest, and decisions about treatment options if they were to develop serious complications with (i) a low likelihood of survival, or (ii) a high likelihood of survival but might become immobile and unable to communicate, or (iii) a high likelihood of survival but might suffer from permanent cognitive impairment. The choice categories include "all treatment I need to live as long as I can", "stop all efforts to keep me alive, allow natural death to happen" and "unsure".

For individuals with advanced illnesses, they were asked about their CPR preferences, decisions related to medical intervention (comfort, limited additional interventions, full treatment), place of care, and place of death. Under the current programme, full treatment considers intubation, mechanical ventilation, and cardioversion. Medical management may also include transfer to intensive care if indicated. Limited additional interventions include comfort measures and may also include oral or intravenous medications. While non-invasive ventilation support is acceptable, endotracheal intubation or long-term life support measures, including admission to intensive care units are not. Comfort measures include reasonable measures made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort, but it does not include intubation.

For place of medical treatment or care, individuals could opt for the home, hospice, nursing home, hospital, a trial of treatment in their homes before considering transfer to a hospital or a hospice, and a trial of treatment in the hospice or nursing home before transfer to a hospital. The documentation also allowed the individual to indicate "no preferences" and "others". For place of death, individuals are asked where they would wish to be if they were left with 2-3 days of life. They could opt for either the home, hospital, hospice or nursing home, and two or more alternatives such as home or hospital, and home or nursing home or hospital.

Measures and data extraction

We extracted data on ACP participant profiles and preferences from the national ACP IT system, and the Tan Tock Seng Hospital ACP database. Data fields related to the nomination of a substitute decision maker(s), preference about the administration of CPR in the event of a cardiac arrest, and end-of-life care preferences were extracted. In addition, for patients diagnosed with advanced illnesses, we extracted their preferences for place of care and death as well.

To ascertain whether the individuals were deceased, the data was linked to death-related data from the National Registry of Birth and Deaths. Every Singaporean resident is issued with a NRIC number. For this study, a project unique identifying number (PUIN) was generated for each NRIC by a third-party vendor, who was not involved in the analysis of the data. The PUIN was then used to link data belonging to each individual person across the datasets.

Data analysis

Descriptive statistics were used to characterise the sample and to summarise the basic characteristics of the data. Frequency distribution tables were created to profile the characteristics of the study samples and to describe the documented end-of-life care preferences. A chi-square test was used to determine whether a statistically significant relationship exists between two or more categorical variables.

We examined the independent effects of age and gender on four different end-of-life care statement of preference. We dichotomised the preferences for: (i) cardiopulmonary resuscitation (CPR) (“attempt” or “do not attempt”), (ii) medical intervention (“treatment” or “comfort measures”), (iii) preferred place of medical treatment (“home” or “others”) and (iv) preferred place of death (“home” or “others”). Multivariable logistic regression was performed to investigate the relationship between age and sex with these preferences. All statistical tests were conducted using Stata version 12 (25), and a two-sided p-value of 0.05 was set as the level of statistical significance.

RESULTS

A total of 3,380 completed ACP documents were captured in the databases, with approximately 90% completed in acute hospitals. The patient characteristics can be seen in Table 1. 60% of the patients were aged 75 years and above, and there was demographic variation across the three types of ACP, with younger age profiles for those who completed the general and disease-specific forms. Among all individuals who completed the ACP, 53.2% (1798/3380) were deceased as at 31 December 2015, with the highest share for PPC. The overall median time between ACP completion and death was 7.27 months (95% CI: 6.35-8.18); 63.2% completed ACP within three months prior to death, 52.9% within six months and 42.3% within 12 months.

Table 1 Profile of individuals by type of ACP.

Variable	**Category**	**Type of ACP**			**Total (n, %)**	**p-value**
		Healthy (n, %)	Chronic illness (n, %)	Advanced illness (n, %)		
Age	< 55 years	77 (11.9)	6 (12.2)	142 (5.3)	225 (6.7)	<0.001
	55–64 years	193 (29.9)	14 (28.6)	259 (9.6)	466 (13.8)	
	65–74 years	203 (31.4)	17 (34.7)	445 (16.6)	665 (19.7)	
	≥ 75 years	173 (26.8)	12 (25.5)	1,839 (68.5)	2,024 (59.9)	
Sex	Female	359 (55.6)	19 (38.8)	1,316 (49.0)	1,694 (50.1)	0.001
	Male	265 (41.0)	28 (57.1)	1,335 (49.7)	1,628 (48.2)	
	Missing	22 (3.4)	2 (4.1)	34 (1.3)	58 (1.7)	
Deceased	Yes	57 (8.8)	10 (20.4)	1,731 (64.5)	1,798 (53.2)	<0.001
	No	589 (91.2)	39 (79.6)	954 (35.5)	1582 (46.8)	
Total		**646 100.0)**	**49 (100.0)**	**2,685 (100.0)**	**3,380 (100.0)**	

Documented preferences

Data related to preferences for end-of-life care are represented in Table 2. For healthy individuals who had completed the general ACP, 1 in 8 persons indicated a preference for life-sustaining treatment. For individuals who had completed the disease-specific form, close to 1 in 3 opted for CPR and life-sustaining treatment, even if the likelihood of surviving the complications of the illness were low or if they were to lose their ability to move around or communicate. However, only 16.3% opted for full treatment if they were to become mentally incapacitated because of their illness.

For individuals with advanced illnesses (Table 3), 5.7% opted for CPR and 5.1% opted for full medical intervention. The majority preferred the initiation of a limited trial of treatment, which would be continued with comfort measures if there was no clinical improvement. Approximately 43.6% of individuals preferred to receive treatment in their homes, but 77.4% of these individuals would consider being transferred to an acute hospital after a trial of care at home. Only 29.7% stated the hospital as their preferred site of care. For place of death, 40.4% preferred dying at home, and only 14.1% preferred the hospital. One highlight is that although only 4.1% did not state any preference or were unsure about the place of care, 23% of respondents did indicate their preferences with regards to the preferred place of death.

Table 2 End-of-life care preferences in general and disease specific ACP forms.

Documented preferences	**N, %**
Healthy individuals (n = 646)	
Appointment substitute decision maker	581 (89.9)
Comfort measures	560 (86.7)
Life-sustaining treatments	79 (12.2)
Individuals with chronic illness (n = 49)	
Appointment 1st substitute decision maker	35 (71.4)
Appointment 2nd substitute decision maker	15 (30.6)
Serious complication with low chance of survival	
Full treatment	16 (32.7)
Stop treatment	31 (63.3)
Serious complication with loss of ability to move around or communicate	
Full treatment	15 (30.6)
Stop treatment	32 (65.3)
Serious complication with mental incapacity	
Full treatment	8 (16.3)
Stop treatment	38 (77.6)
Cardiopulmonary resuscitation	
Attempt	14 (28.6)
Do not attempt	19 (38.8)
Do not attempt if doctor believes low survival chances	14 (28.6)
Individuals with advanced illness (n = 2685)	
Appointment 1st substitute decision maker	2,526 (94.1)
Appointment 2nd substitute decision maker	1,357 (50.5)
Cardiopulmonary resuscitation	
Attempt	152 (5.7)
Do not attempt	2,511 (93.5)
Do not attempt if doctor believes low survival chances	22 (0.8)
Medical intervention	
Full treatment	138 (5.1)
Limited additional interventions	1,851 (68.9)
Comfort measures only	677 (25.2)
Unsure	19 (0.7)
Preferred place of medical treatment	
Home	265 (9.8)
Hospital	798 (29.7)
Nursing home	166 (6.2)

Documented preferences	N, %
Hospice	131 (4.9)
Trial of treatment before consider transfer to hospital	
Home	908 (33.8)
Nursing home	269 (10.0)
Hospice	28 (1.0)
Others (no preference, unsure)	110 (4.1)
Missing	10 (0.4)
Preferred place of death	
Patient's home	1,084 (40.4)
Hospital	379 (14.1)
Nursing home	160 (5.9)
Hospice	156 (5.8)
Home or hospital/nursing home/hospice	112 (4.2)
Healthcare institution (hospital or nursing home or hospice)	177 (6.7)
Others (no preference, unsure)	617 (23.0)

ACP: Advance Care Planning; CPR: Cardiopulmonary Resuscitation

Relationship between patient and SDM

The share of individuals who had appointed a substitute decision-maker varied across the three types of ACP. The rates of nomination were, however, lower for those who completed the general and disease-specific plans. For the PPC, only 8% of individuals did not identify a substitute decision-maker (Table 3). From Table 4.4, 78% of individuals nominated their immediate family (spouse, children, grandchildren) to speak on their behalf if they were incapacitated. Only a small percentage nominated non-related persons. Most ACP discussions also took place in the acute care setting.

Table 3 Relationship with substitute decision maker.

Type of substitute	Type of ACP			Total	p-value
	Healthy (n, %)	Chronic illness (n, %)	Advanced illness (n, %)		
Spouse	185 (28.6)	8 (16.3)	320 (11.9)	513 (15.2)	<0.001
Child, child-in-law, or grandchild	230 (35.6)	20 (40.8)	1869 (69.6)	2119 (62.7)	
Other relatives and friends	136 (21.1)	2 (4.1)	266 (9.9)	404 (12.0)	
Others (including healthcare professionals)	14 (2.2)	1 (2.0)	10 (0.4)	25 (0.7)	
Missing	81 (12.5)	18 (36.7)	220 (8.2)	319 (9.4)	
Total	**646 (100.0)**	**49 (100.0)**	**2685 (100.0)**	**3380 (100.0)**	

Relationship between preferred place of care and place of death

Table 4 assessed the relationship between place of care and place of death. The results indicated that there was a high level of agreement and strong correlation in preferences related to being cared for at home and dying at home. Other than this, the place of care is not synonymous with where they would like to die at. Close to 1 in 3 individuals who preferred the hospital as the location of care, had also opted for home as the place of death.

Table 4 Preferred place of care and preferred place of death.

Place of Death	**Place of Care**							
	Home	Hospital	Hospice	Nursing home	Home to Hospital/ Hospice	Hospice to NH/Hospital	Others$^{\#}$	Total
Home	90.9**	31.1	9.9	5.4	57.3	12.1	12.7	40.4
Hospital	0.8	30.3**	0.0	1.2	9.7	13.7	2.7	14.1
Hospice	0.8	3.1	67.9^{NS}	0.6	2.6	3.3	4.5	5.8
Nursing home	0.4	0.4	0.0	70.5^{NS}	0.2	12.1*	0.0	6.0
Home or hospital/ nursing home/ hospice	1.9	3.5	1.5	0.0	8.0**	2.0	2.7	4.4
Healthcare institution	0.4	4.4	4.6	6.6*	1.2	30.3*	19.1	6.6
Others$^{\#}$	4.9	26.7	16.0	15.7	20.9	26.7	58.2**	22.7

Note: #: no preferences, unsure; *p<0.05; **p<0.01

Relationship between treatment preferences and patient profile

As age and sex were not correlated with preferences for healthy and chronically ill individuals, the results were excluded. Table 5 illustrates the results from a logistic regression to assess the impact of age and sex on the preferences of those with advanced illnesses. Those aged 75 years and above were more likely to not opt for CPR and comfort measures, compared to younger individuals. Care at home or having a trial of care at home was the preferred option for the older age group. Similarly, older people exhibited a stronger likelihood of preferring to die at home. There were no significant gender differences in preferences for CPR. However, there was a higher likelihood of females opting for full treatment than comfort measures. This is also consistent with the relatively lower odds of choosing home as the site of care and place of death, compared to males.

Table 5 Multivariable logistic regression of preferences by age and sex with 2,685 subjects who had completed the PPC form.

Preferred plan of care	Age ≥75 vs. Age <75	Female vs. Male
	Adjusted OR (95% CI)	Adjusted OR (95% CI)
CPR		
Attempt vs. Do not attempt	0.31 (018-0.54)	1.56 (0.87-2.79)
Medical intervention		
Treatment vs. Comfort measures	0.32 (0.17-0.62)	2.35 (1.18-4.68)
Preferred place of medical treatment		
Home & trial at home vs. Others	1.52 (1.23-1.89)	0.69 (0.57-0.84)
Preferred place of death		
Home vs. Others	1.29 (1.03-1.61)	0.70 (0.57-0.85)

Model includes variables: age and sex
CPR: Cardiopulmonary Resuscitation; OR: Odds Ratio; C.I.: Confidence Interval

DISCUSSION

This is the first study to have quantified actual decisions about end-of-life care, in a relatively large clinical sample in Singapore. Other published studies have adopted a survey design to elicit preferences as part of research (14, 15, 26). The findings offered insights into decisions made under real-life situations, where the stated preferences were supposed to reflect goals of care of the individual. Singapore stands apart being an Asian country that is strongly influenced by Western culture where the people have a strong desire for independence together with a collectivist mentality (27). The results of this study could therefore be of relevance to other Asian countries that are also experiencing rapid socioeconomic and demographic transitions.

In our study, most individuals nominated their family members to speak on their behalf if they were incapacitated, which is similar to what was observed in other studies (28). Among healthy and chronically ill patients, the majority did not opt for CPR or other life-sustaining measures. Among those with advanced illness, more than 90% preferred not to attempt CPR, but more than 70% still preferred to receive some form of active medical treatment at the end-of-life, rather than comfort care. In this national sample, approximately 4 in 10 chose to be cared for and to die at home. Other Singaporean studies examined the preferences of nursing home residents (29) and those who received care in a day care centre (16). These studies similarly found that while most individuals did not opt for CPR, they did express a preference to receive some form of active treatment (16, 29).

In 2014, the Lien Foundation, a Singapore philanthropic house, commissioned a community-based survey to determine the death attitudes and the level of awareness about hospice and palliative care. The survey reported that 70% and 77% of the surveyed individuals would prefer to be cared for, and to die at home respectively (17). Preferences for medical treatment at home, and for home deaths were significantly lower in our sample. Public opinions often do not coincide with the views of individuals who are close to the end-of-life (20). Other research, such as those examining health state valuation, have pointed out the differences between these two groups (30); reflecting different priorities and changing experiences. The complexity of choices also grows as death draws near (31). When healthy participants are asked to make decisions regarding hypothetical scenarios about death and dying, the 'shock' or fear that he or she experiences (32) about potentially dying in an unfamiliar environment, could sway decisions towards the familiar – meaning the home. Juxtaposed against other priorities, such as pain and symptom management, and alleviating caregiver burden, the “cost” of maintaining one’s decision to die at home may also increase (33). At the same time, the fear of the unfamiliar could decrease over time, as patients increasingly adapt to new living and care arrangements in other settings, such as nursing homes or hospices (34). One in five individuals have been found to change their preferences over time (18).

We also found that, although the preferred place of care and place of death are related, they are not equivalent. While only a small percentage of individuals did not have strict preferences about where they are being cared for, almost 1 in 4 individuals expressed that they had no preferred place of death. Other studies have similarly indicated that these two dimensions are not equivalent, although healthcare professionals may use them interchangeably in practice (35).

In our study, the time between ACP completion and death was 7.3 months. While there is no objective optimal timing (36), this is relatively shorter than the median times (14 - 37 months) reported in literature (37, 38). Given that the discussion about preferences should occur before physical or mental incapacitation, earlier initiation can be beneficial to the patients. At the same time, it is important to strike a balance because conducting the ACP conversation too early when preferences are still unstable (39) could lead to unrealistic choices based on hypothesised scenarios (37). ACP initiation should take into account patient and family receptivity, and ideally, precede major health deterioration that could lead to decisional incapacitation (40). Different diseases have different pathways of functional declines (41), which also needs to be considered.

In our sample of patients with advanced illnesses, we found that age was positively associated with preferences to withhold life-sustaining treatments, which was similar to the findings of several studies (42, 43). We found that individuals older than 75 years were more likely to opt for the home as the place of care and death; but other studies reported that younger individuals more strongly prefer home as the place of care (44), or that age did not have a significant effect (45). Cultural differences, in the meaning assigned to the "home" as a place of care and death, or even the availability of alternative palliative care facilities in different countries, could have resulted in the mixed evidence. For instance, due to the availability of inpatient palliative care units in Japan, older individuals had stronger preferences for the patient palliative care unit as the site of care than home (44). Our finding, that females were less likely to prefer to be cared for and die at home, was similarly reported in other studies (46, 47). This could reflect the general longer life expectancy of females compared to males. This reduced likelihood of spousal support at the end-of-life could make home less preferred as an option (48).

Policy & practice implications

Currently, efforts to implement ACP are focused on the elderly and those with advanced illnesses. Based on the numbers of completed disease-specific forms, the take-up by chronically ill individuals is very low. While better integration of ACP with chronic disease management efforts or more rapid expansion of ACP to the outpatient and community settings could assist in improving coverage, additional resources would concurrently be needed to assist hospitals to expand coverage to younger adults, and bringing ACP conversations forward in the life-cycle of an individual. Building community awareness of, and acceptance towards ACP will be crucial.

Policies should also consider a range of perspectives and preferences, especially of sub-populations that they will most immediately affect. Preferences elicited from surveys can be viewed as an aspirational target that is achievable if practical barriers were eradicated. Additionally, due to the relatively high proportion of individuals who still preferred hospital as the location of care, policy-makers still need to focus on improving the end-of-life care experience in formal healthcare institutions, while also expanding home palliative care capacity to cater to those who preferred home as the first place of care, and place of death.

Limitations

The sample comprised largely the patients receiving care in the acute care hospitals, and the results may not be generalisable for patients in the community care settings or to other individuals who have elected not to participate in ACP. Individuals who had completed the ACP documentation could be less death-avoidant, and therefore, have different preferences compared to others. Other studies have also highlighted the importance of the family and care context on care preferences. A recent systematic review highlighted the lack of research evidence on ethnicity and religion, which is also absent from this study. Future research should explore the influence of these pertinent elements including a closer examination of the influence of different illnesses (advanced malignancy, end-stage organ failure or neuro-degenerative diseases) on end-of-life care preferences.

CONCLUSION

This study identified that most of the individuals in our sample, regardless of health status, preferred not to proceed with life-sustaining treatments across a spectrum of health scenarios. However, individuals with advanced illnesses still preferred to receive some form of active support, e.g. non-invasive ventilation support; or oral and intravenous drug administration. Our results imply that policies should consider not just home-based end-of-life care, but also actively focus on the quality of end-of-life care in hospitals, since many individuals still opt for them as the site of care.

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Footnotes

Contributors Woan Shin Tan, and Ram Bajpai conceived and designed the study, obtained, analysed, interpreted the data, drafted and revised the article. Chan Kee Low, Andy Hau Yan Ho and Josip Car conceived the study, participated in the interpretation of results, and revised the article. All authors were involved in revising the manuscript critically for important intellectual content and have given final approval of the final version of the manuscript.

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Competing interests None declared.

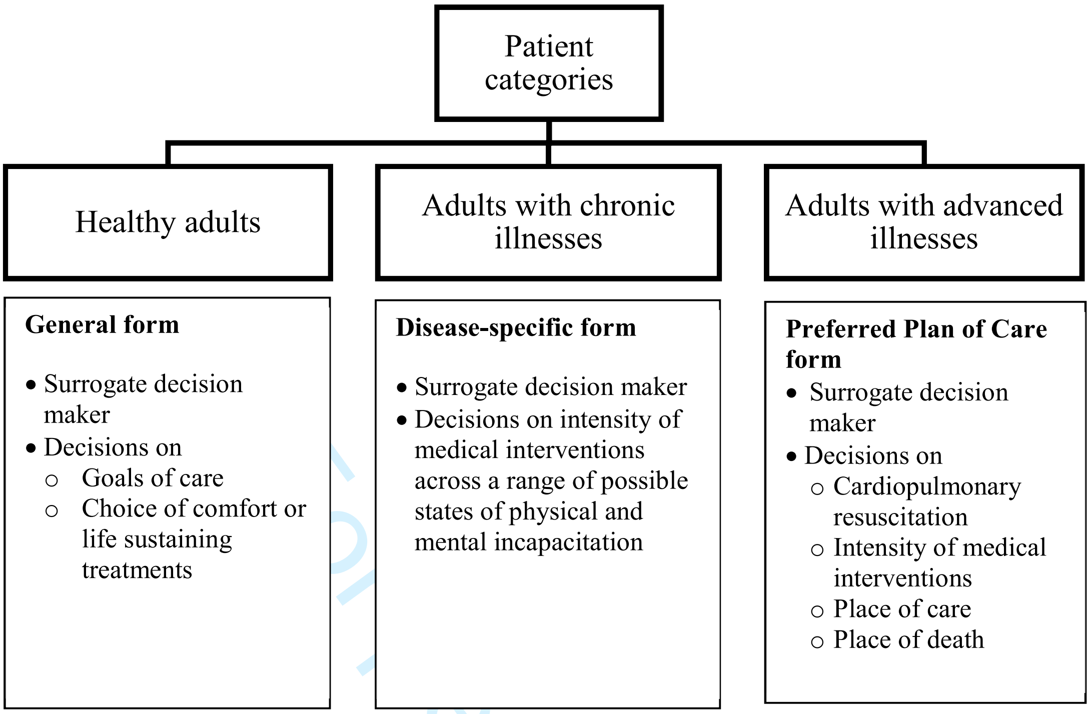
Patient consent None declared.

Ethics approval Ethics approval was obtained from the institutional review boards of Nanyang Technological University [Ref: IRB-2016-03-010] and the National Healthcare Group's Domain Specific Review Board [Ref: 2016/00739].

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data available.

Figure 1 End-of-life care decisions by health status.


Patient categories
Healthy adults
Adults with chronic illnesses
Adults with advanced illnesses
General form
• Surrogate decision maker
• Decisions on
○ Goals of care
○ Choice of comfort or life sustaining treatments
Disease-specific form
• Surrogate decision maker
• Decisions on intensity of medical interventions across a range of possible states of physical and mental incapacitation
Preferred Plan of Care form
• Surrogate decision maker
• Decisions on
○ Cardiopulmonary resuscitation
○ Intensity of medical interventions
○ Place of care
○ Place of death

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3-4
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6-7
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	9
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9-12
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	9-12
Bias	9	Describe any efforts to address potential sources of bias	21
Study size	10	Explain how the study size was arrived at	9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	11-12
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	12
		(*b*) Describe any methods used to examine subgroups and interactions	12
		(*c*) Explain how missing data were addressed	14
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N.A.
		(*e*) Describe any sensitivity analyses	N.A.
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	12-13
		(b) Give reasons for non-participation at each stage	N.A.
		(c) Consider use of a flow diagram	N.A.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	13
		(b) Indicate number of participants with missing data for each variable of interest	13
Outcome data	15*	Report numbers of outcome events or summary measures	14-15
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	17
		(*b*) Report category boundaries when continuous variables were categorized	13
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N.A.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15-17
Discussion			
Key results	18	Summarise key results with reference to study objectives	17-20
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	21
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17-21
Generalisability	21	Discuss the generalisability (external validity) of the study results	21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	27

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

A retrospective cohort analysis of real-life decisions about end-of-life care preferences in a Southeast Asian country

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Primary Subject Heading:	Palliative care
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Keywords:	advance care planning, patient preferences, place of care, place of death, cross sectional study

A retrospective cohort analysis of real-life decisions about end-of-life care preferences in a Southeast Asian country

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ABSTRACT

Objective To describe the end-of-life care preferences of individuals, and to examine the influence of age and gender on these preferences.

Design, setting, and participants A retrospective cohort study was conducted. Participants included all adults (≥ 21 years old) (n=3,380) who had completed a statement of their preferences as part of a national ACP programme in Singapore. Data were extracted from the national and Tan Tock Seng Hospital ACP database.

Main Measures End-of-life care preferences were obtained from the ACP document and differentiated by health status (healthy, chronically ill, or diagnosed with advanced illnesses). To analyse the data, descriptive statistics and logistic regression analysis were used.

Results Across healthy, and chronically ill patients, the majority did not opt for cardiopulmonary resuscitation (CPR) or other life-sustaining measures. Among individuals with advanced illnesses, 94% preferred not to attempt CPR but 69% still preferred to receive some form of active medical treatment. Approximately 40% chose to be cared for, and to die at home. Age and sex significantly predict preferences in those with advanced illnesses. Older age (>=75 years) showed higher odds for home as preferred place of care (odds ratio (OR): 1.52; 95% CI: 1.23-1.89) and place of death (OR: 1.29; 95%CI: 1.03-1.61) and lower odds for CPR (OR: 0.31; 95%CI: 0.18-0.54) and full treatment (OR: 0.32; 95% CI: 0.17-0.62). Being female was associated with lower odds for home as preferred place of care (OR): 0.69; 95% CI: 0.57-0.84) and place of death (OR: 0.70; 95% CI: 0.57-0.85) and higher odds for full treatment (OR: 2.35; 95% CI: 1.18-4.68).

Conclusion The majority preferred to not proceed with life-sustaining treatments, but there was still a strong preference to receive some form of limited treatment. Better understanding of end-of-life care preferences through ACP can better guide end-of-life care programme planning, and resource allocation decisions.

ARTICLE SUMMARY

Strengths and limitations of this study

- Examined real-life end-of-life preferences of individuals across different health states
- Comprehensive coverage of a large sample of patients who received care from seven acute care hospitals, and twelve different social care providers in Singapore
- Examined the association of end-of-life care preferences with age and sex but was unable to examine the correlation with other covariates due to data limitation
- Individuals who voluntarily completed their advance care plans could be less death-avoidant
- Prospective study will allow for gathering of more variables that influence end-of-life care preferences which this study lacks

INTRODUCTION

Most societies that are experiencing a rapidly ageing population would encounter challenges in providing high quality end-of-life care to its population. In many jurisdictions, through a process of Advance Care Planning (ACP) an individual could designate a health care decision-maker, and specify decisions regarding life-sustaining treatments in the event of decisional incapacitation. Research has found ACP to empower patients with a greater peace of mind (1), improve the level of agreement with regards to end-of-life care between patient and surrogate, reduce decisional conflict (2) and improve their satisfaction with care (3). The likelihood of dying at their preferred place was also higher among individuals who had completed an ACP (4); the transition between acute and terminal care is often smoother (5). ACP was also associated with avoiding or reducing unnecessary life-sustaining treatments (1, 4), increasing the incidence of out-of-hospital and out-of-intensive care, and increasing the probability of dying at home (6-9).

With this perspective, the Singapore government launched a comprehensive national ACP programme, “Living Matters”, in 2011. “Living Matters” is based on the Respecting Choices® programme at the Gundersen Health System in Wisconsin, US. Primarily, the programme aims to systematise the elicitation and documentation of medical and care preferences (10); with a longer-term goal of normalising death and dying conversations in the community (11, 12). Listed amongst populations that are ageing most rapidly in the world, this is a timely effort, as the need to cater for health care, including end-of-life care of the population, is expected to intensify alongside the doubling of the elderly population (13).

Surveys have been conducted locally to profile the end-of-life care preferences across different patients and community-based samples (14-17). However, surveys often require individuals to respond to a single question about their preferred place of death, based on a hypothetical end-of-life scenario (18) without having to trade-off against other priorities or account for other than one's personal concerns. Therefore, choices elicited through a survey could reflect what is preferred under more "ideal" circumstances. Since an illness impacts the individual biologically as well as socially (19), the survey process may not mirror real-life decision-making processes well (20).

Therefore, in this article, we review the demographics and end-of-life care preferences, as documented in an Advance Care Plan. Given that end-of-life care preferences could differ across different health states and over one's life cycle (21), preferences are profiled according to the health status of those expressing them. Additionally, we also examined the effect of age and gender on stated preferences.

METHODOLOGY

Advance Care Planning programme

The "Living Matters" programme comprised three integrated components: (1) provision of patient educational materials; (2) trained and certified ACP facilitators who assist individuals with ACP; (3) development of an IT system to enable easily storage, and retrieval of ACP forms (22, 23). The programme has adopted a staged approach that considers a person's state of health and allows ACP to be conducted in phases across one's life-time. The conversations can then be individualised based on one's health status, which is broadly categorised as healthy, diagnosed with complex chronic illnesses or diagnosed with advanced illnesses.

Currently, referral to ACP and the staging of one's health status is largely based on clinical judgement. Individual clinicians also assess the individual patient's readiness to discuss end-of-life care issues. In practice, a social care or health care professional may facilitate a conversation between the patient, and his/her family members to explore his/her values, beliefs and how this impacts preferences towards medical care at the end-of-life. ACP is not legally binding in Singapore and therefore, there is no need to engage a lawyer for its discussion or documentation (24). All participating patients are encouraged to identify a substitute decision-maker (SDM), who can make health care decisions on their behalf in the event of incapacitation.

Different questions and standardised forms apply to each of the three health states (healthy, chronically ill, with advanced illness) (Figure 1). Individuals identify a substitute decision-maker and also establish the goals of care relevant to their disease stage. They are intended to update their decisions as they transit health states. For instance, questions regarding disease-related complications are not applicable to a healthy individual whereas, for an individual with a poor prognosis, questions related to disease-related complications may no longer be applicable. Rather, they may be concerned about care during the terminal phase.

End-of-life care preferences are documented in an IT system after obtaining the patient's concurrence that they accurately reflect their decisions. These recorded preferences are accessible to different providers across the acute care continuum.

Study design and population

This is a retrospective cohort study that included all individuals aged 21 years and above, who have completed their ACP between January 2011 and December 2015 across all participating acute care hospitals, specialist care centres, and social care providers in Singapore.

Patient and public involvement

Patients were not involved in the design of the study although end-of-life care preferences documented as part of routine clinical care were aggregated and reported in this study. As only anonymised data were analysed, data were not disseminated to the patients.

Ethics and consent

Ethics approval was obtained from the institutional review board of Nanyang Technological University and Domain Specific Review Board of the National Healthcare Group, Singapore. As this is a retrospective database study, written informed consent was waived by both boards.

Elicited preferences by health status

There were three different forms, general, disease specific, and the preferred plan of care (PPC) form, to cater to individuals at different health stages (healthy, chronically ill, advanced illness).

For healthy adults, they were asked about their preferences related to the goals of care when the probability of recovery or survival is low. The choices provided were: “make comfort the goal of my care and do not prolong my life in this condition” or “continue to provide all necessary life-sustaining treatment until outcomes happen to me which I find unacceptable”.

For individuals with chronic conditions, the wishes documented in an ACP form specifies preferences about CPR during cardiac arrest, and decisions about treatment options if they were to develop serious complications with (i) a low likelihood of survival, or (ii) a high likelihood of survival but might become immobile and unable to communicate, or (iii) a high likelihood of survival but might suffer from permanent cognitive impairment. The choice categories include “all treatment I need to live as long as I can”, “stop all efforts to keep me alive, allow natural death to happen” and “unsure”.

For individuals with advanced illnesses, they were asked about their CPR preferences, decisions related to medical intervention (comfort, limited additional interventions, full treatment), place of care, and place of death. Under the current programme, full treatment considers intubation, mechanical ventilation, and cardioversion. Medical management may also include transfer to intensive care if indicated. Limited additional interventions include comfort measures and may also include oral or intravenous medications. While non-invasive ventilation support is acceptable, endotracheal intubation or long-term life support measures, including admission to intensive care units are not. Comfort measures include reasonable measures made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort, but it does not include intubation.

For place of medical treatment or care, individuals could opt for the home, hospice, nursing home, hospital, a trial of treatment in their homes before considering transfer to a hospital or a hospice, and a trial of treatment in the hospice or nursing home before transfer to a hospital. The documentation also allowed the individual to indicate “no preferences” and “others”. For place of death, individuals are asked where they would wish to be if they were left with 2-3 days of life. They could opt for either the home, hospital, hospice or nursing home, and two or more alternatives such as home or hospital, and home or nursing home or hospital.

Measures and data extraction

We extracted data on available personal characteristics of patients (age/gender) and preferences from the national ACP IT system, and the Tan Tock Seng Hospital ACP database. Data fields related to the nomination of a substitute decision maker(s), preference about the administration of CPR in the event of a cardiac arrest, and end-of-life care preferences were extracted. In addition, for patients diagnosed with advanced illnesses, we extracted their preferences for place of care and death as well.

To ascertain whether the individuals were deceased, the data was linked to death-related data from the National Registry of Birth and Deaths. Every Singaporean resident is issued with a NRIC number. For this study, a project unique identifying number (PUIN) was generated for each NRIC by a third-party vendor, who was not involved in the analysis of the data. The PUIN was then used to link data belonging to each individual person across the datasets.

Data analysis

Descriptive statistics were used to characterise the sample and to summarise the basic characteristics of the data. Frequency distribution tables were created to profile the characteristics of the study samples and to describe the documented end-of-life care preferences. A chi-square test was used to determine whether a statistically significant relationship exists between two or more categorical variables.

We examined the independent effects of age and gender on four different end-of-life care statement of preference. We dichotomised the preferences for: (i) cardiopulmonary resuscitation (CPR) ("attempt" or "do not attempt"), (ii) medical intervention ("treatment" or "comfort measures"), (iii) preferred place of medical treatment ("home" or "others") and (iv) preferred place of death ("home" or "others"). Multivariable logistic regression was performed to investigate the relationship between age and sex with these preferences. All statistical tests were conducted using Stata version 12 (25), and a two-sided p-value of 0.05 was set as the level of statistical significance.

RESULTS

A total of 3,380 completed ACP documents were captured in the databases, with approximately 90% completed in acute hospitals. The patient characteristics can be seen in Table 1. 60% of the patients were aged 75 years and above, and there was demographic variation across the three types of ACP, with younger age profiles for those who completed the general and disease-specific forms. Among all individuals who completed the ACP, 53.2% (1798/3380) were deceased as at 31 December 2015, with the highest share for individuals with advanced illnesses. The overall median time between ACP completion and death was 7.27 months (95% CI: 6.35-8.18); 63.2% completed ACP within three months prior to death, 52.9% within six months and 42.3% within 12 months.

Table 1 Profile of individuals by type of ACP.

Variable	**Category**	**Type of ACP**			**Total (n, %)**	**p-value**
		Healthy (n, %)	Chronic illness (n, %)	Advanced illness (n, %)		
Age	< 55 years	77 (11.9)	6 (12.2)	142 (5.3)	225 (6.7)	<0.001
	55–64 years	193 (29.9)	14 (28.6)	259 (9.6)	466 (13.8)	
	65–74 years	203 (31.4)	17 (34.7)	445 (16.6)	665 (19.7)	
	≥ 75 years	173 (26.8)	12 (25.5)	1,839 (68.5)	2,024 (59.9)	
Sex	Female	359 (55.6)	19 (38.8)	1,316 (49.0)	1,694 (50.1)	0.001
	Male	265 (41.0)	28 (57.1)	1,335 (49.7)	1,628 (48.2)	
	Missing	22 (3.4)	2 (4.1)	34 (1.3)	58 (1.7)	
Deceased	Yes	57 (8.8)	10 (20.4)	1,731 (64.5)	1,798 (53.2)	<0.001
	No	589 (91.2)	39 (79.6)	954 (35.5)	1582 (46.8)	
Total		**646 100.0)**	**49 (100.0)**	**2,685 (100.0)**	**3,380 (100.0)**	

Documented preferences

Data related to preferences for end-of-life care are represented in Table 2. For healthy individuals who had completed the general ACP, 1 in 8 persons indicated a preference for life-sustaining treatment. For individuals who had completed the disease-specific form, close to 1 in 3 opted for CPR and life-sustaining treatment, even if the likelihood of surviving the complications of the illness were low or if they were to lose their ability to move around or communicate. However, only 16.3% opted for full treatment if they were to become mentally incapacitated because of their illness.

For individuals with advanced illnesses (Table 3), 5.7% opted for CPR and 5.1% opted for full medical intervention. The majority preferred the initiation of a limited trial of treatment, which would be continued with comfort measures if there was no clinical improvement. Approximately 43.6% of individuals preferred to receive treatment in their homes, but 77.4% of these individuals would consider being transferred to an acute hospital after a trial of care at home. Only 29.7% stated the hospital as their preferred site of care. For place of death, 40.4% preferred dying at home, and only 14.1% preferred the hospital. One highlight is that although only 4.1% did not state any preference or were unsure about the place of care, 23% of respondents did not indicate their preferences with regards to the preferred place of death.

Table 2 End-of-life care preferences in general and disease specific ACP forms.

Documented preferences	**N, %**
Healthy individuals (n = 646)	
Appointment substitute decision maker	581 (89.9)
Comfort measures	560 (86.7)
Life-sustaining treatments	79 (12.2)
Individuals with chronic illness (n = 49)	
Appointment 1st substitute decision maker	35 (71.4)
Appointment 2nd substitute decision maker	15 (30.6)
Serious complication with low chance of survival	
Full treatment	16 (32.7)
Stop treatment	31 (63.3)
Serious complication with loss of ability to move around or communicate	
Full treatment	15 (30.6)
Stop treatment	32 (65.3)
Serious complication with mental incapacity	
Full treatment	8 (16.3)
Stop treatment	38 (77.6)
Cardiopulmonary resuscitation	
Attempt	14 (28.6)
Do not attempt	19 (38.8)
Do not attempt if doctor believes low survival chances	14 (28.6)
Individuals with advanced illness (n = 2685)	
Appointment 1st substitute decision maker	2,526 (94.1)
Appointment 2nd substitute decision maker	1,357 (50.5)
Cardiopulmonary resuscitation	
Attempt	152 (5.7)
Do not attempt	2,511 (93.5)
Do not attempt if doctor believes low survival chances	22 (0.8)
Medical intervention	
Full treatment	138 (5.1)
Limited additional interventions	1,851 (68.9)
Comfort measures only	677 (25.2)
Unsure	19 (0.7)
Preferred place of medical treatment	
Home	265 (9.8)
Hospital	798 (29.7)
Nursing home	166 (6.2)
Hospice	131 (4.9)

Documented preferences	N, %
Trial of treatment before consider transfer to hospital	
Home	908 (33.8)
Nursing home	269 (10.0)
Hospice	28 (1.0)
Others (no preference, unsure)	110 (4.1)
Missing	10 (0.4)
Preferred place of death	
Patient's home	1,084 (40.4)
Hospital	379 (14.1)
Nursing home	160 (5.9)
Hospice	156 (5.8)
Home or hospital/nursing home/hospice	112 (4.2)
Healthcare institution (hospital or nursing home or hospice)	177 (6.7)
Others (no preference, unsure)	617 (23.0)

ACP: Advance Care Planning; CPR: Cardiopulmonary Resuscitation

Relationship between patient and SDM

The share of individuals who had appointed a substitute decision-maker varied across the three types of ACP. The rates of nomination were, however, lower for those who completed the general and disease-specific plans. For the PPC, only 8% of individuals did not identify a substitute decision-maker (Table 3). From Table 4.4, 78% of individuals nominated their immediate family (spouse, children, grandchildren) to speak on their behalf if they were incapacitated. Only a small percentage nominated non-related persons. Most ACP discussions also took place in the acute care setting.

Table 3 Relationship with substitute decision maker.

Type of substitute	Type of ACP			Total	p-value
	Healthy (n, %)	Chronic illness (n, %)	Advanced illness (n, %)		
Spouse	185 (28.6)	8 (16.3)	320 (11.9)	513 (15.2)	<0.001
Child, child-in-law, or grandchild	230 (35.6)	20 (40.8)	1869 (69.6)	2119 (62.7)	
Other relatives and friends	136 (21.1)	2 (4.1)	266 (9.9)	404 (12.0)	
Others (including healthcare professionals)	14 (2.2)	1 (2.0)	10 (0.4)	25 (0.7)	
Missing	81 (12.5)	18 (36.7)	220 (8.2)	319 (9.4)	
Total	**646 (100.0)**	**49 (100.0)**	**2685 (100.0)**	**3380 (100.0)**	

Relationship between preferred place of care and place of death

Table 4 assessed the relationship between place of care and place of death. The results indicated that there was a high level of agreement and strong correlation in preferences related to being cared for at home and dying at home. Other than this, the place of care is not synonymous with where they would like to die at. Close to 1 in 3 individuals who preferred the hospital as the location of care, had also opted for home as the place of death.

Table 4 Preferred place of care and preferred place of death.

Place of Death	Place of Care							
	Home	Hospital	Hospice	Nursing home	Home to Hospital/ Hospice	Hospice to NH/Hospital	Others$^{\#}$	Total
Home	90.9^{**}	31.1	9.9	5.4	57.3	12.1	12.7	40.4
Hospital	0.8	30.3^{**}	0.0	1.2	9.7	13.7	2.7	14.1
Hospice	0.8	3.1	67.9^{NS}	0.6	2.6	3.3	4.5	5.8
Nursing home	0.4	0.4	0.0	70.5^{NS}	0.2	12.1^{*}	0.0	6.0
Home or hospital/ nursing home/ hospice	1.9	3.5	1.5	0.0	8.0^{**}	2.0	2.7	4.4
Healthcare institution	0.4	4.4	4.6	6.6^{*}	1.2	30.3^{*}	19.1	6.6
Others$^{\#}$	4.9	26.7	16.0	15.7	20.9	26.7	58.2^{**}	22.7

Note: #: no preferences, unsure; *p<0.05; **p<0.01

Relationship between treatment preferences and patient profile

As age and sex were not correlated with preferences for healthy and chronically ill individuals, the results were excluded. Table 5 illustrates the results from a logistic regression to assess the impact of age and sex on the preferences of those with advanced illnesses. Those aged 75 years and above were more likely to not opt for CPR and comfort measures, compared to younger individuals. Care at home or having a trial of care at home was the preferred option for the older age group. Similarly, older people exhibited a stronger likelihood of preferring to die at home. There were no significant gender differences in preferences for CPR. However, there was a higher likelihood of females opting for full treatment than comfort measures. This is also consistent with the relatively lower odds of choosing home as the site of care and place of death, compared to males.

Table 5 Multivariable logistic regression of preferences by age and sex with 2,685 subjects who had completed the PPC form.

Preferred plan of care	Age ≥75 vs. Age <75	Female vs. Male
	Adjusted OR (95% CI)	Adjusted OR (95% CI)
CPR		
Attempt vs. Do not attempt	0.31 (018-0.54)	1.56 (0.87-2.79)
Medical intervention		
Treatment vs. Comfort measures	0.32 (0.17-0.62)	2.35 (1.18-4.68)
Preferred place of medical treatment		
Home & trial at home vs. Others	1.52 (1.23-1.89)	0.69 (0.57-0.84)
Preferred place of death		
Home vs. Others	1.29 (1.03-1.61)	0.70 (0.57-0.85)

Model includes variables: age and sex
CPR: Cardiopulmonary Resuscitation; OR: Odds Ratio; C.I.: Confidence Interval

DISCUSSION

This is the first study to have quantified actual decisions about end-of-life care, in a relatively large clinical sample in Singapore. Other published studies have adopted a survey design to elicit preferences as part of research (14, 15, 26). The findings offered insights into decisions made under real-life situations, where the stated preferences were supposed to reflect goals of care of the individual. Singapore stands apart being an Asian country that is strongly influenced by Western culture where the people have a strong desire for independence together with a collectivist mentality (27). The results of this study could therefore be of relevance to other Asian countries that are also experiencing rapid socioeconomic and demographic transitions.

In our study, most individuals nominated their family members to speak on their behalf if they were incapacitated, which is similar to what was observed in other studies (28). Among healthy and chronically ill patients, the majority did not opt for CPR or other life-sustaining measures. Among those with advanced illness, more than 90% preferred not to attempt CPR, but more than 70% still preferred to receive some form of active medical treatment at the end-of-life, rather than comfort care. In this national sample, approximately 4 in 10 chose to be cared for and to die at home. Other Singaporean studies examined the preferences of nursing home residents (29) and those who received care in a day care centre (16). These studies similarly found that while most individuals did not opt for CPR, they did express a preference to receive some form of active treatment (16, 29).

In 2014, the Lien Foundation, a Singapore philanthropic house, commissioned a community-based survey to determine the death attitudes and the level of awareness about hospice and palliative care. The survey reported that 70% and 77% of the surveyed individuals would prefer to be cared for, and to die at home respectively (17). Preferences for medical treatment at home, and for home deaths were significantly lower in our sample. Public opinions often do not coincide with the views of individuals who are close to the end-of-life (20). Other research, such as those examining health state valuation, have pointed out the differences between these two groups (30); reflecting different priorities and changing experiences. The complexity of choices also grows as death draws near (31). When healthy participants are asked to make decisions regarding hypothetical scenarios about death and dying, the 'shock' or fear that he or she experiences (32) about potentially dying in an unfamiliar environment, could sway decisions towards the familiar – meaning the home. Juxtaposed against other priorities, such as pain and symptom management, and alleviating caregiver burden, the “cost” of maintaining one’s decision to die at home may also increase (33). At the same time, the fear of the unfamiliar could decrease over time, as patients increasingly adapt to new living and care arrangements in other settings, such as nursing homes or hospices (34). One in five individuals have been found to change their preferences over time (18).

We also found that, although the preferred place of care and place of death are related, they are not equivalent. While only a small percentage of individuals did not have strict preferences about where they are being cared for, almost 1 in 4 individuals expressed that they had no preferred place of death. Other studies have similarly indicated that these two dimensions are not equivalent, although healthcare professionals may use them interchangeably in practice (35).

In our study, the time between ACP completion and death was 7.3 months. While there is no objective optimal timing (36), this is relatively shorter than the median times (14 - 37 months) reported in literature (37, 38). Given that the discussion about preferences should occur before physical or mental incapacitation, earlier initiation can be beneficial to the patients. At the same time, it is important to strike a balance because conducting the ACP conversation too early when preferences are still unstable (39) could lead to unrealistic choices based on hypothesised scenarios (37). ACP initiation should take into account patient and family receptivity, and ideally, precede major health deterioration that could lead to decisional incapacitation (40). Different diseases have different pathways of functional declines (41), which also needs to be considered.

In our sample of patients with advanced illnesses, we found that age was positively associated with preferences to withhold life-sustaining treatments, which was similar to the findings of several studies (42, 43). We found that individuals older than 75 years were more likely to opt for the home as the place of care and death; but other studies reported that younger individuals more strongly prefer home as the place of care (44), or that age did not have a significant effect (45). Cultural differences, in the meaning assigned to the “home” as a place of care and death, or even the availability of alternative palliative care facilities in different countries, could have resulted in the mixed evidence. For instance, due to the availability of inpatient palliative care units in Japan, older individuals had stronger preferences for the patient palliative care unit as the site of care than home (44). Our finding, that females were less likely to prefer to be cared for and die at home, was similarly reported in other studies (46, 47). This could reflect the general longer life expectancy of females compared to males. This reduced likelihood of spousal support at the end-of-life could make home less preferred as an option (48).

Policy & practice implications

Currently, efforts to implement ACP are focused on the elderly and those with advanced illnesses. Based on the numbers of completed disease-specific forms, the take-up by chronically ill individuals is very low. While better integration of ACP with chronic disease management efforts or more rapid expansion of ACP to the outpatient and community settings could assist in improving coverage, additional resources would concurrently be needed to assist hospitals to expand coverage to younger adults, and bringing ACP conversations forward in the life-cycle of an individual. Building community awareness of, and acceptance towards ACP will be crucial.

Policies should also consider a range of perspectives and preferences, especially of sub-populations that they will most immediately affect. Preferences elicited from surveys can be viewed as an aspirational target that is achievable if practical barriers were eradicated. Additionally, due to the relatively high proportion of individuals who still preferred hospital as the location of care, policy-makers still need to focus on improving the end-of-life care experience in formal healthcare institutions, while also expanding home palliative care capacity to cater to those who preferred home as the first place of care, and place of death.

Limitations

The sample comprised largely the patients receiving care in the acute care hospitals. As such, the results may not be generalisable for patients in the community care settings or to other individuals who have elected not to participate in ACP. Individuals who had completed the ACP documentation could be less death-avoidant, and therefore, have different preferences compared to others. We were only able to examine the relationship between preferences and patient age and sex due to limited availability of data. Other studies (49) have also highlighted the importance of the family and care context on care preferences. A recent systematic review (50) highlighted the lack of research evidence on ethnicity and religion, which is also absent from this study. Future research should explore the influence of these pertinent elements including a closer examination of the influence of different illnesses (advanced malignancy, end-stage organ failure or neuro-degenerative diseases) on end-of-life care preferences.

CONCLUSION

This study identified that most of the individuals in our sample, regardless of health status, preferred not to proceed with life-sustaining treatments across a spectrum of health scenarios. However, individuals with advanced illnesses still preferred to receive some form of active support, e.g. non-invasive ventilation support; or oral and intravenous drug administration. Our results imply that policies should consider not just home-based end-of-life care, but also actively focus on the quality of end-of-life care in hospitals, since many individuals still opt for them as the site of care.

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Footnotes

Contributors Woan Shin Tan, and Ram Bajpai conceived and designed the study, obtained, analysed, interpreted the data, drafted and revised the article. Chan Kee Low, Andy Hau Yan Ho and Josip Car conceived the study, participated in the interpretation of results, and revised the article. All authors were involved in revising the manuscript critically for important intellectual content and have given final approval of the final version of the manuscript.

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Competing interests None declared.

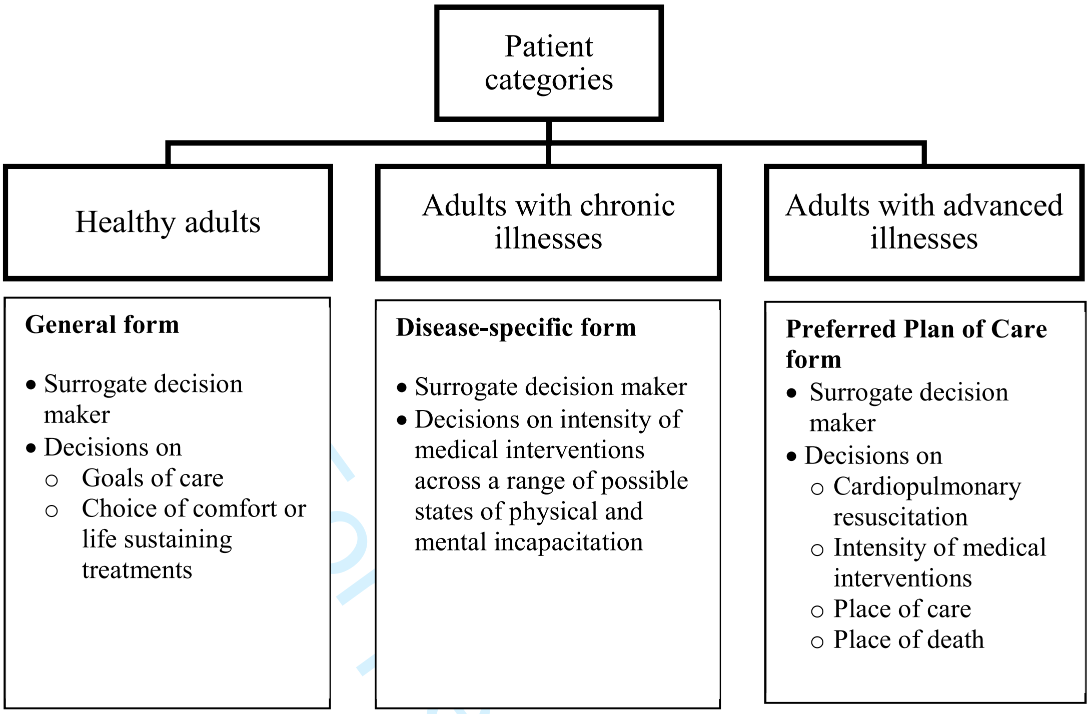
Patient consent None declared.

Ethics approval Ethics approval was obtained from the institutional review boards of Nanyang Technological University [Ref: IRB-2016-03-010] and the National Healthcare Group's Domain Specific Review Board [Ref: 2016/00739].

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data available.

Figure 1 End-of-life care decisions by health status.


Patient categories
Healthy adults
Adults with chronic illnesses
Adults with advanced illnesses
General form
• Surrogate decision maker
• Decisions on
○ Goals of care
○ Choice of comfort or life sustaining treatments
Disease-specific form
• Surrogate decision maker
• Decisions on intensity of medical interventions across a range of possible states of physical and mental incapacitation
Preferred Plan of Care form
• Surrogate decision maker
• Decisions on
○ Cardiopulmonary resuscitation
○ Intensity of medical interventions
○ Place of care
○ Place of death

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3-4
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	6-7
Objectives	3	State specific objectives, including any prespecified hypotheses	7
Methods			
Study design	4	Present key elements of study design early in the paper	9
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9-12
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	9-12
Bias	9	Describe any efforts to address potential sources of bias	21
Study size	10	Explain how the study size was arrived at	9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	11-12
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	12
		(*b*) Describe any methods used to examine subgroups and interactions	12
		(*c*) Explain how missing data were addressed	14
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N.A.
		(*e*) Describe any sensitivity analyses	N.A.
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	12-13
		(b) Give reasons for non-participation at each stage	N.A.
		(c) Consider use of a flow diagram	N.A.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	13
		(b) Indicate number of participants with missing data for each variable of interest	13
Outcome data	15*	Report numbers of outcome events or summary measures	14-15
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	17
		(*b*) Report category boundaries when continuous variables were categorized	13
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N.A.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15-17
Discussion			
Key results	18	Summarise key results with reference to study objectives	17-20
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	21
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17-21
Generalisability	21	Discuss the generalisability (external validity) of the study results	21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	27

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.