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Awareness and Preferences for End-of-Life Care: A Study Protocol for a Survey of Chinese Frail Elderly Home Residents in Hong Kong

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ABSTRACT

Introduction: Existing literature on attitudes toward End-of-Life Care (EoLC) covers the general public but has little information on the frail elderly population. The aim of the current study is to investigate awareness and preferences with respect to EoLC among Chinese frail elderly home residents by conducting cross-sectional surveys via face-to-face interviews.

Methods and analysis: Surveys including a resident version and a family version were developed based on the existing literature and our pilot interviews. The targeted participants are 400 frail elderly home residents (aged ≥65 years old) and 200 family caregivers as matched with elderly respondents. Purposive sampling will be used as each elderly home will help to recruit five to fifteen elderly participants for the study. Descriptive analysis and modeling will be used to examine awareness, preferences, and related factors, as well as to compare resident responses with those of their family caregivers.

Ethics and dissemination: The cross-sectional survey has obtained IRB approval. Confidentiality and safety issues will be carefully observed. The results of the study will be disseminated through international conferences, peer-reviewed academic journal publications, and a report in plain language to be shared with partner elderly homes.

Strengths and limitations of this study:

- Survey versions were developed to inquire into the attitudes of both the frail elderly and family caregivers.
- For the first time, elderly attitudes on EoLC surveys cover all main areas of Hong Kong.
- The cross-sectional design of this study cannot conclude causality.

INTRODUCTION

The population of Hong Kong (HK) ranks top in life expectancy around the globe, and the percentage of its ageing population continues to rise.[1] The government officially projects that the percentage of elderly residents aged 65 and above will keep growing from over one million to 2.61 million in 2058 (36% of the HK population).[1, 2] This is much higher than the global estimate of the elderly population (21.1% percent in 2050).[3] At present, the demands for residential elderly care services in HK remain overwhelming. Though a total of 32,418 places were offered in Residential Care Homes for Elderly (RCHE), as reported by the Social Welfare Department of HK in March 2018, the June 2018 update of the central waiting list contains 39,209 applicants for subsidized residential care facilities.[4, 5] The average waiting time to enter a residential care setting is 24 months.[6]

Due to priority consideration for waitlisted applicants, frailty is one of the primary characteristics taken into account for elderly being admitted to RCHE settings. By definition, frailty refers to the vulnerable state in which there is an increased risk of hospitalization, deterioration in functioning, and mortality.[7] Additionally, there is a significant interaction effect reported between frailty and depression among the HK elderly in terms of their subjective health.[8] Prevalence of depression among the elderly Chinese of HK is reported to be the highest (12%) in long-term care institutions as compared to other residential settings, as reported in a study with a total sample of 56,000.[9] According to their cohort study findings, depressive symptoms independently predicted the risk of suicide. Therefore, it is critically important to study the attitudes of institutionalized elderly people with high frailty status toward their end-of-life care (EoLC).

EoLC attitudes have attracted increasing attention in peer-reviewed journals.[1, 10, 11] Studies demonstrated that the general public awareness of Advance Directives (AD) was low.[1, 10, 11] Moreover, a recent systematic review[12] that summarized EoLC studies in HK in the past decade reported low awareness of Advanced Care Planning (ACP) among frail elderly people. Potential barriers to research include the challenges of engaging elderly homes given that service providers are motivated to protect their residents and may hesitate before to aid researchers. The frail elderly are particularly under studied and thus their voices have not been sufficiently heard among academics, politicians, and a wider public audience. Our study will help to bridge this knowledge gap. Even though we found the most recent report on prevalence of general public preferences regarding EoLC and place of death[1, 13] these results were generated from telephone landline surveys, which did not reach the frail elderly population living in RCHE. The percentage of their studied participants who answered the brief home-phone interview calls may not represent the views of elderly people on these sensitive topics. Face-to-face interviews with the frail elderly will help to gain a better understanding of their attitudes.

Meanwhile, it is urgent to update our knowledge about the region as the only studies on EoLC among elderly home residents in HK were conducted roughly 10 years ago.[6, 12, 14] The influential factors for their preferences hypothesized from existing literature enables us to explore additional possible predictors. The socio-economic predictors of higher awareness of EoLC and preference to die outside of hospitals were clearly lacking in previous studies.[14] The present study will use a comprehensive design to explore the under-researched topic of EoLC preferences of a neglected population: the frail elderly.

Understanding this population is necessary in order to provide better quality of elderly care and to develop new services for unmet needs based on existing system strengths, particularly in facing the rapid ageing trend. This is consistent with the World Health Organization's (WHO) initiative to build an age-friendly environment.[3] The need to enhance quality of dying is recognized in Hong Kong. Before developing new services, the first step is to understand the preferences of the public, especially elderly people. The current study could lend support for feasible possibilities of future intervention research. In addition, our comprehensive survey includes important variables such as depression, pain, Activities of Daily Living (ADL), suicidal ideation, and frailty, which will definitely enrich the research area.[2, 6-15] The implications from these findings will help the government to improve the allocation of resources in developing EoLC services. Researchers will be able to further identify future directions for public education and other types of intervention to meet the EoLC needs of HK's frail elderly citizens.

Within the family context, caregivers' attitudes are also crucial, as they play a significant role in future decision making in the case that an elderly family member loses the capacity to make decisions on their own and does not have an AD. A recent systematic review by Wang and Chan shows[12] that family caregivers in HK have been an insufficiently studied population in research. The dyad questionnaire in the current study is designed to match the caregiver's understanding/expectation of the elderly family member's preference and the elderly's own wish as expressed to research staff directly. It aims to be elderly-centered. Referring to a recent dyad study,[16] agreement between caregiver's expectation and the elderly's own wish is low or at

best moderate. Caregiver rating on uncertainty is high. Families often find making EoLC decisions very stressful. Those with problematic family dynamics tend to opt for aggressive treatment.[17, 18] Their findings highlight the importance of communication rather than assuming the families know what the patients want regarding their EoLC. It is unknown whether the family situation of HK's frail elderly is similar to previous research elsewhere or not. Thus, further investigation of this in our analysis to compare the perspectives is worthwhile.

Research questions

i) What is the level of awareness of terms such as living will, EoLC, and life-sustaining treatment in Hong Kong among the frail elderly and their family caregivers?

ii) What is the elderly's personal exposure to such terms?

iii) What are their preferences with regard to AD, ACP, EoLC, and place of death?

iv) Are there any demographic and personal features related to preference and level of awareness?

v) Is there any relationship between the elderly's expression of preferences and their caregiver's expectation?

Outcomes

i) Primary outcome: The frail elderly preferred place of death.

ii) Secondary outcomes: The frail elderly's level of awareness and preferences with regard to AD, ACP, and EoLC; the elderly and their family caregivers' dyad agreement on elderly's preferences, and family caregivers' awareness of these terms.

METHODS AND ANALYSIS

We did not directly include Patient and Public Involvement (PPI) in this study; however, the survey was developed after consultation with public representatives such as experienced staff members who work with the target population. The revision of the survey content based on pilot responses took their comments into account.

The inclusion criteria for the frail elderly participants are as follows:

i) At least 65 years of age;

ii) Chinese in HK homes who can speak and understand either Cantonese or Mandarin;

iii) Pre-frail or frail (rating 1-5 on FRAIL)

The exclusion criteria for frail elderly participants are:

i) Cognitive impairment (scoring 5 or below on the Abbreviated Mental Test [AMT]).[25] To screen for ineligibility due to cognitive impairment, the Chinese AMT will be used.

ii) Communication problems due to functional impairment (for example, deafness, aphasia)

The inclusion criteria for family caregiver participants are as follows

i) HK Chinese adults (18 years of age or above) who can speak and understand Cantonese or Mandarin.

The exclusion criteria for family caregiver participants are:

(i) Communication problems due to functional (deafness, aphasia) or intellectual impairment.

A structured questionnaire (one version for the frail elderly and the other version their family caregivers) has been developed based on the objectives of the current study and with reference to recent publication on similar topics.[1, 10, 11] Additional scales were integrated to design this comprehensive survey study. The PI and the Co-Is ascertained face validity based on literature and research experience in the area. The Chinese questionnaires have been viewed by a panel of six Hong Kong local experts, including one geriatric doctor, one clinical psychologist, two nurses, and two social workers. The first elderly questionnaire has been pilot tested on one site with a sample of 12 elderly Chinese to test for feasibility. We then revised the survey in preparation for the main study. After that the pilot test, the experts were invited to judge the content validity of the questions for the second time as the questionnaires were developed. The content validity index was calculated as excellent (CVI/AVR = 0.87 for elderly and 0.98 for caregiver survey).

The Abbreviated Mental Test (AMT) and FRAIL screening tools will be applied to select our participants. The interview for the frail elderly will be conducted if they are deemed eligible. The questionnaire contains seven parts: (A) Demographics and functioning (personal profile); (B) Healthcare experiences and attitude; (C) Expectations of EoLC, (D) Advanced Care Planning

experience and attitude; (E) Advance Directives awareness, experience, and attitude (F) Ideal terminal/death environment (preferences on places of care and eventual death); and (G) Quality of Life.

(A) Demographic information including age, sex, educational level, marital status, religion, financial source, type of nursing home, family members, previous living arrangement, self-reported health and pain severity, and bereavement experience, etc., will be collected. To assess daily functioning, frailty, depressive symptoms, and suicidal ideation, we will use the following respective scales, 10-item Barthel Index on ADL,[8] 5-item FRAIL,[19-21] Geriatric Depression Scale GDS-4, and a single-item suicidal ideation assessment.[22] If the family and the staff in residential care settings give permission for such information to be released, we would obtain the most recent records from their files. The records must be up-to-date within the past 6 months. If not, we will conduct our own collection.

(B) The participants will be asked to share their experience of and attitude toward life sustaining treatment and previous hospitalization according to questions we have devised.

(C) The participants will be asked to rate their opinions on decision making with regard to life-sustaining treatment in a hypothetical dying scenario, and their attitudes on quality of life at the end of life. The hypothetical dying scenario will be described in one phrase as “becoming seriously ill but with no cure available” for themselves.

(D) The participants will be asked about their awareness and experience or participation in ACP, their attitudes and preferred communication with others, as well as their reasons for ACP.

(E) Participants will be asked about their awareness of a living will and AD, and about their process in formulating their written preferences on medical decisions and AD. The reasons behind their choices and the persons who introduced these topics to them will also be explored.

(F) The participants will be asked to rate their opinions on their hypothetical dying situation, i.e., the ideal places of their terminal care and death. They will be asked about their preferences regarding dying alone or having certain persons around them during their own eventual death.

(G) The McGill Quality of Life (M-QoL-HK) questionnaire will be used to measure Quality of Life among HK adults. Through a ten-point Likert Scale of 17 items, M-QoL measures four dimensions, including physical health, psychological/mental health, spiritual wellbeing, and overall quality of life. The items in M-QoL are considered applicable to both elderly, palliative care patients, and caregivers by authors in the validated context of Hong Kong.[23]

The questionnaire for family caregivers contains eight parts: (A) Their relationship with the elderly; (B) Healthcare experiences and attitudes, and preferences for EoLC; (C) Expectations of EoLC, (D) Advanced Care Planning experiences and attitudes; (E) awareness, experience, and attitudes toward Advance Directives (F) Ideal terminal/dying situations (preferences with respect to places of care and eventual death); (G) Quality of Life; and (H) Supplementary information on demographics, financial support for caregiving, bereavement experience, and self-rated health (personal profile). The contents are similar to the elderly survey version with slight changes in wording to include an item that measures the caregivers' understanding of the elderly's own perspective. Most of the questions are close-ended, while there are open-ended options for the caregivers to express their own opinions.

For both the elderly and family surveys, there is a small ending section where interview staff can write their observation notes on respondents' emotions. Interviewers may also mark any words such as 'euthanasia' or 'hastened death' if these are mentioned during the conversations.[24]

Completion time for the interview is estimated to be 30-45 minutes. The trained research assistants will read out and explain all survey items one by one to the respondents to ensure the quality of the data collection. Furthermore, the respondents are not allowed to change their answer once the questions have been answered.

A pilot questionnaire has been completed on one site of a sample of 12 in an elderly home prior to the main study. Feasibility of the survey content was assessed. During our pilot survey interviews, we found the majority (10 out of 12 participants) who agreed to join the study were happy or felt it was acceptable to discuss EoLC issues with us, while the remaining 2 expressed discomfort or refused to continue in the middle of the conversation. Similarly, existing literature shows that elderly people in Hong Kong facilities are willing to talk about issues related to death and dying.[6] Most of the participants (11 out of 12) in our pilot were considered as belonging to either the category of Pre-frail or Frail. This offers our survey the advantage of gaining first-hand knowledge about the elderly's preferences and experiences. Furthermore, we plan to share our findings in the form of an explanation after the interview so that participants know where to obtain further details as needed. This survey study itself can increase public awareness of EoLC

among the elderly. In the pilot studies, only one participant out of the 12 elderly had heard of AD and ACP before our interviews. This low level of awareness is consistent with the report of earlier surveys, where 96% never heard of AD in Chu's study and 85.7% in Chung's study. [1, 13]

We plan to partner with 32 elderly homes with an average of 12 residents from each home. Under the most conservative scenario (assuming the true proportion is 50%), a sample of 384 elderly residents will be required to give a 95% confidence interval for the proportion of people who would prefer dying in elderly homes, with a margin of error of 5%. To cater for inter-correlation within residents in the same home, we assume ICC to be 0.05. We will expect to interview 400 elderly in order to collect their responses to the survey. Assuming that around half of these elderly people will have family caregivers to join the study, 200 family caregivers will be interviewed.

Using a purposive sampling method, we plan to select elderly homes in all main regions of HK (Hong Kong Island, Kowloon, and the New Territories) by sending out invitations via mail and by convenient professional networks. The managers of the elderly care homes will be approached via phone calls and asked permission to let us interview their elderly residents. Written invitations will be sent to family caregivers with requests for information release of their elderly relatives. The elderly residents in the homes will be invited in person to participate in face-to-face survey interviews. The family caregivers can call to schedule caregiver interviews

(also optional) with our research staff at a time and place convenient to both as mutually agreed. Each matching pair will be included in our pool of studied dyads.

The facility staff will introduce us to the elderly candidates. There will be no monetary incentives offered to either the participants or the agencies involved. During the recruitment process, the research assistant (RA) will explain the study to the potential participants either in a private room (bedside/chairside) or in a corner of a common room to protect privacy. After seeking oral or implicit consent from residents to participate, the RA will administer the AMT and the five-item Frailty scale to screen out ineligible subjects based on our exclusion criteria. The Co-I or the RA will then conduct a face-to-face individual interview with the participant using our designed questionnaire. Trained RAs will collect data during the interviews on either paper or tablet form, depending on the interviewer and Internet availability. Participants therefore have the convenient option to fill out the surveys on their mobile smartphones or tablets.[26] Paper-based surveys will serve as a backup option. Missing items will be noted as 999 automatically in the database. IBM SPSS version 25 and Mplus will be used for the statistical analyses.

Descriptive analysis will first be conducted on demographics. Response frequencies for each measure will be tabulated and the corresponding proportions will be calculated by dividing the frequency by the number of respondents. We plan to apply Logistic Regression Analysis to investigate independent predictors of our outcomes of interests, for example, the participants'

preference to die in elderly residential homes. The associations of sociodemographic characteristics, frailty, depression, and functioning status with the outcomes will be analyzed.

We will apply Kappa Statistics to examine paired results between the frail elderly and their family caregivers. Preferences for life sustaining treatment will be expressed in 3x2 tables and described in terms of percentage agreement and the kappa coefficient. The level of agreement will be described using indices such as 'agreement index' developed in literature on treatment preferences. Where a caregiver could accurately interpret an elderly person's preference in LST, whether that was for active treatment, against LST, or uncertain, they will gain a score of one. Thus, we will use a total score of 0 (no ability) through 8 (full ability) to know or estimate the family members' preferences in treatment for elderly residents who were at terminal stages from survey hypothetical scenarios. Combined agreement scores from all matched pairs of family caregivers and elderly respondents will represent overall agreement in the survey sample. Finally, we plan to calculate the association between elderly participants and family caregivers' characteristics and agreement scores through multiple linear regression.

ETHICS AND DISSEMINATION

The cross-sectional survey has been approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (IRB Reference number: UW 18-443). To respect the principles of human dignity and voluntary participation in the study, a comprehensive verbal explanation and a comprehensive information sheet will be provided to the participants (family caregivers and the frail elderly) during the recruitment period, prior to

the commencement of data collection. The purpose and procedure of the study as well as the risks and benefits of participation will be explained. Respondents will be encouraged to clarify any queries related to the study with the research staff. Oral consent will be obtained from elderly participants before commencing the individual interviews. For their family members, respondents can opt for either oral or written consent. Participation will be entirely voluntary, and respondents will be informed of their rights to withdraw or refuse to give information at any time without incurring penalties or deprivation of services.

There is a chance that these interviews may cause some stress for elderly participants beyond what is typical in their casual daily conversations given that as the survey covers death-related content. In the pilot interviews, signs of stress appeared occasionally as expected. Participants were asked whether they wanted to continue or not, and then their wishes were respected. Similarly, in the future interviews during the proposed study, the survey process will be paused in cases when participants are willing to continue despite stress to reduce potential harm to participants. The RA and the Co-I will closely observe the reactions of the elderly participants. Additionally, relaxation techniques will be taught to the elderly participants on site as needed. This will be documented in our survey and referred to staff for appropriate follow-up. Moreover, positive answers to the item on suicidal ideation item and those with depression symptoms at the cutoff score of 2 or above will be brought to attention of the elderly home staff.[23]

The results of the proposed cross-sectional study will be reported with reference to the international statement in the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist for cross-sectional studies.[27] The findings will be disseminated through international conference presentations and peer-reviewed academic journal

publications. Meanwhile, a report in plain language will be shared with our partner elderly homes. The evidence gathered from this study has the potential to benefit research on EoLC both locally and internationally, and to further inform practitioners on the desires and the EoLC needs of the elderly and their caregivers. It is very important to share the knowledge that we gain on the preferences of frail elderly with professionals in healthcare sectors, such as physicians, direct service staff, and the larger community. Understanding their wishes can be a great step towards developing better quality EoLC.

AUTHOR CONTRIBUTIONS

CL, PC, and BY conceptualized the survey design. BY and PC drafted the manuscript protocol. BY prepared the IRB application and the amendment with collaborative input. BY and XX conducted pilot survey interviews. All the authors contributed to the development of the survey with revisions and approved the final version of the manuscript.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

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

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
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
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
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
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
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
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
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
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
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

*Give information separately for exposed and unexposed groups.

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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Preferences for End-of-Life Care: A Study Protocol for a Cross-sectional Survey of Chinese Frail Elderly Home Residents in Hong Kong

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Preferences for End-of-Life Care: A Study Protocol for a Cross-sectional Survey of Chinese Frail Elderly Home Residents in Hong Kong

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ABSTRACT

Introduction: Existing literature on attitudes toward end-of-life care (EoLC) covers the general public but has little information on the frail elderly population. The aim of the current study is to investigate the preferences of Chinese frail elderly home residents with respect to EoLC by conducting cross-sectional surveys.

Methods and analysis: Surveys, including resident and family versions, were developed based on the existing literature and our pilot interviews. The targeted participants were 400 frail elderly home residents (aged ≥65 years old) and 200 family caregivers. Purposive sampling will be used as each elderly home will help to recruit 5 to 15 elderly participants for the study. Descriptive analysis and modelling will be used to examine preferences on EoLC and related factors, as well as to compare the responses of elderly home residents with those of their family caregivers.

Ethics and dissemination: The cross-sectional survey has obtained IRB approval. Confidentiality and safety issues will be carefully observed. The results of the study will be disseminated through international conferences, peer-reviewed academic journal publications, and a report in plain language to be shared with partner elderly homes.

Strengths and limitations of this study:

- Survey versions were developed to inquire into the preference of both the frail elderly home residents and family caregivers.
- For the first time, surveys on elderly attitudes towards EoLC cover all main areas of Hong Kong.
- The cross-sectional design of this study cannot conclude causality.

INTRODUCTION

End-of-life care (EoLC) attitudes have increasingly attracted attention in peer-reviewed journals.[1-4] The literature indicates that EoLC for terminally ill patients can include many challenges, for example, access to services, quality of care, awareness, attitudes, communication, and decision making.[4] Advance care planning (ACP) and advance directives (ADs) have been promoted in order to discover patient attitudes towards their EoLC,[5] with the benevolent intention that these processes help to honour their wishes or preferences for a good death. An AD is one of the potential outcomes of participation in ACP. Both ADs and ACP involve the patients' understanding of life-sustaining treatment (LST).[6] Several studies have demonstrated that the awareness of AD is low in the Chinese populations.[1-3, 5] Moreover, a recent systematic review summarised 107 EoLC studies in Hong Kong in the past decade reported a primary focus on AD rather than ACP.[4] Studies of Chinese family attitudes towards ACP present mixed findings according to Lee's review in 2014.[5] Therefore, our study aims to investigate EoLC preferences and relevant factors, such as ACP and AD awareness, preferences concerning LST, decision-making, and preferred place of death, by conducting original surveys with frail elderly home residents and their family caregivers.

By definition, frailty refers to a vulnerable state in which there is an increased risk of hospitalisation, deterioration in functioning, and mortality.[7] Frail elderly people are particularly understudied, and thus their voices have rarely been heard by academics, politicians, or the wider public. Though we found the most recent report on the prevalence of Hong Kong general public preferences regarding EoLC and preferred place of death,[1, 8] these results were generated from telephone landline surveys. The public participants who joined the brief phone interview may not represent the views of frail elderly home residents on these sensitive topics.

The landline phone calls could not reach the frail elderly population living in residential care homes for the elderly (RCHEs), including nursing homes, care and attention homes, and other types of homes that provide comprehensive care for dependent people.[9] Our study will help to bridge this knowledge gap. Face-to-face interviews with frail elderly home residents will help to gain a better understanding of their attitudes.

The present study is significant as the population of Hong Kong ranks top in life expectancy around the globe, and the percentage of its ageing population is rising.[1, 9] The government officially projects that the percentage of elderly residents aged 65 and above will continue to grow from over one million to 2.61 million in 2058 (36% of the Hong Kong population).[1, 10] This is much higher than estimates of the global elderly population (21.1% percent in 2050).[11] At present, the demands for residential elderly care services in Hong Kong remain overwhelming, with average waiting time as long as 24 months for admission.[12] Due to priority considerations, frailty is one of the primary characteristics taken into account for elderly being admitted to Hong Kong RCHEs.[9] Therefore, it is critically important to study the elderly home residents with pre-frail or frail statuses as they are most likely to receive EoLC in residential homes.[9]

Meanwhile, knowledge about the region must be urgently updated as the only studies on EoLC among elderly home residents in Hong Kong were conducted roughly ten years ago.[4, 6, 12] Hypothesising those factors that influence their preferences from the existing literature enables us to explore additional possible predictors. The present study will use a comprehensive design to explore the under-researched topic of EoLC preferences of an understudied population: frail elderly home residents. Within families, caregivers' attitudes are also crucial, as they play a significant role as surrogate decision-makers in the future circumstance of an elderly family

member, who does not have an AD or ACP, losing the capacity to make decisions on their own. Families often find making EoLC decisions very stressful.[13, 14] The systematic review by Wang and Chan shows that family caregivers in Hong Kong have also been an insufficiently studied population.[4] Thus, it is worth further investigation of caregiver's attitudes, and so we include this comparative perspective in our analysis. This is consistent with the World Health Organization's initiative to build an age-friendly environment.[11] To enhance quality of EoLC in RCHEs, our survey findings will be a helpful reference to further identifying some directions for public education and other interventions in order to meet the needs of Hong Kong's frail elderly home residents.

Research questions

Phase 1: Survey of elderly home residents

What is the level of awareness of such terms as living will, AD, or ACP in Hong Kong among the frail elderly, and what are their preferences with regard to ACP, decision-making, LST, AD, EoLC, and preferred place of death?

Phase 2: Family caregiver survey

What is the level of awareness of such terms such as living will, AD, or ACP in Hong Kong among family caregivers, and what are their attitudes of elderly family members' preferences?

METHODS AND ANALYSIS

Design

Prior to the main cross-sectional study, a pilot questionnaire has been completed on one site with a sample of 12 participants in an RCHE. The feasibility of the survey content was assessed. During our pilot survey interviews, we found the majority (10 out of 12) of participants who agreed to join the study were happy or felt it was acceptable to discuss EoLC issues with us, while the remaining two elderly lost interest or refused to continue in the middle of the interviews. Withdrawal was respected. Afterwards, no severe distress was reported or observed. Similarly, the existing literature shows that elderly people in Hong Kong facilities are willing to talk about issues related to death and dying.[12] This offers our survey the advantage of gaining first-hand knowledge about the elderly's preferences and experiences. In the pilot, only one participant out of the 12 elderly had heard of AD or ACP before our interviews. This low level of awareness is consistent with earlier surveys that reported that 96% and 85.7% of people surveyed had never heard of AD.[1,8]

We conducted four phone interviews with family caregivers as a pilot for the family version of the survey. Three of the four interviews were completed, but the only dropout occurred in the middle when she suspected that our interview was actually an attempt to sell something. Feasibility and acceptance of our survey appears high among frail elderly home residents and family caregivers in Hong Kong. We have made modifications to the version for the elderly to shorten the questionnaire to reduce burden of participation. We have added explanations of ACP and AD in plain language, so that it is easier for lay participants to understand. We have provided more choices on why participants do or do not want to consider initiating ACP or an AD based on pilot findings.

Outcomes

i) Phase 1 Primary outcome: Preferences of the frail elderly on ACP.

ii) Phase 1 Secondary outcomes: The frail elderly's level of awareness and preferences with regard to LST, decision-making, AD, preferred place of death, and quality of life.

iii) Phase 2 Primary outcome: Level of agreement between Family caregivers' preferences and those of elderly's on ACP for elderly home residents.

iv) Phase 2 Secondary outcomes: Family caregivers' awareness of these terms and preferences with regard to LST, decision-making, ACP, AD, and preferred place of death.

Participants

Phase 1 Frail elderly home residents

The inclusion criteria for the frail elderly participants are as follows:

i) At least 65 years of age;

ii) Chinese in elderly homes who can speak and understand either Cantonese or Mandarin;

iii) Either pre-frail or frail status (rating 1-5 on FRAIL).[15]

The exclusion criteria for frail elderly participants are:

i) Cognitive impairment (scoring five or below on the abbreviated mental test [AMT]).[16]

To screen for ineligibility due to cognitive impairment, the Chinese AMT will be used.

ii) Communication problems due to functional impairment (for example, deafness or aphasia).

Phase 2 Family caregivers

The inclusion criteria for family caregiver participants are as follows

i) Hong Kong Chinese adults (18 years of age or above) who can speak and understand Cantonese or Mandarin.

The exclusion criteria for family caregiver participants are:

(i) Communication problems due to functional (deafness or aphasia) or intellectual impairment.

Recruitment

We plan to partner with 32 local elderly homes with an average of 12 residents from each home. Under the most conservative scenario (assuming the true proportion is 50%), a sample of 384 elderly residents will be required to give a 95% confidence interval for the proportion of people who would prefer to have communication on ACP with a margin of error of 5%. To cater for inter-correlation within residents in the same home, we assume ICC to be 0.05. We will expect to interview 400 elderly in order to collect their responses to the survey in the first phase. Assuming that around half of these elderly people will have family caregivers willing to join the study, 200 family caregivers will be interviewed in the second phase.

Using a purposive sampling method, we plan to select elderly homes in all main regions of Hong Kong (Hong Kong Island, Kowloon, and the New Territories) by sending out invitations via mail and by convenient professional networks. The managers of the elderly care homes will

be approached via phone calls and asked permission to let us interview their elderly residents. The elderly residents in the homes will be invited in person to participate in face-to-face survey interviews. The family caregivers can choose to join caregiver interviews via either face-to-face or via phone survey with our research staff at a time convenient as mutually agreed.

The facility staff will introduce us to the elderly candidates. There will be no monetary incentives offered to either the participants or the agencies involved. During the recruitment process, the research assistant (RA) will explain the study to the potential participants either in a private room (bedside/chairside) or in a corner of a common room to protect privacy. After seeking oral consent from residents to participate, the RA will administer the AMT and the five-item Frailty scale to screen out ineligible ones based on our exclusion criteria. The RA will then conduct a face-to-face individual interview with the participant using our designed questionnaire. Trained RAs will collect data during the interviews on either paper or tablet form, depending on the Internet availability. Participants therefore have the convenient option to fill out the surveys on their mobile smartphones or tablets. Paper-based surveys will serve as a backup option.

Survey interviews

A structured questionnaire (one version for the frail elderly and the other version for their family caregivers) has been developed based on the objectives of the current study and with reference to recent publication on similar topics.[1-3] Additional scales were integrated to design this comprehensive survey study. The authors ascertained face validity based on literature and research experience in the area. The Chinese questionnaires have been viewed by a panel of six Hong Kong local experts, including one geriatric doctor, one clinical psychologist, two nurses,

and two social workers. The first elderly questionnaire has been pilot tested on one site with a sample of 12 elderly Chinese to test for feasibility. We then revised the survey in preparation for the main study. After that the pilot test, the experts were invited to judge the content validity of the questions for the second time as the questionnaires were developed. The content validity index was calculated as excellent (CVI/AVR = 0.87 for elderly and 0.98 for caregiver survey).

Phase 1 Measurement

The AMT and FRAIL screening tools will be applied to select our participants. The interview for the frail elderly will be conducted if they are deemed eligible. The questionnaire contains seven parts: (A) Demographics and functioning (personal profile); (B) Healthcare experiences and attitude; (C) Expectations of EoLC, (D) Advanced Care Planning experience and attitude; (E) Advance Directives awareness, experience, and attitude (F) Ideal terminal/death environment (preferences on places of care and eventual death); and (G) Quality of Life.

(A) Demographic information including age, sex, educational level, marital status, religion, financial source, type of nursing home, family members, self-reported health and pain severity, and bereavement experience, etc., will be collected. To assess daily functioning, frailty, depressive symptoms, and suicidal ideation, we will use the following respective scales, 10-item Barthel Index on ADL,[17] 5-item FRAIL,[15] Geriatric Depression Scale GDS-4, and a single-item suicidal ideation assessment.[18]

(B) The participants will be asked to share their experience of and attitude toward life sustaining treatment and previous hospitalisation according to questions we have devised.

(C) The participants will be asked to rate their opinions on decision making with regard to LST in a hypothetical dying scenario, and their attitudes on quality of life at the end of life. The

hypothetical dying scenario will be described in one phrase as "becoming seriously ill but with no cure available" for themselves.

(D) The participants will be asked about their awareness and experience or participation in ACP, their attitudes and preferred communication with others, as well as their reasons for rejecting the idea of ACP.

(E) Participants will be asked about their awareness of a living will and AD, and about their current consideration in formulating their written preferences on medical decisions and AD. The reasons behind their choices and the persons who introduced these topics to them will also be explored.

(F) The participants will be asked to rate their opinions on their hypothetical dying situation, i.e., the ideal places of their terminal care and death. They will be asked about their preferences regarding dying alone or having certain persons around them during their own eventual death.

(G) The McGill Quality of Life (M-QoL-HK) questionnaire will be used to measure Quality of Life among Hong Kong adults. Through a ten-point Likert Scale of 17 items, M-QoL measures four dimensions, including physical health, psychological/mental health, spiritual wellbeing, and overall quality of life. The items in M-QoL are considered applicable to both elderly, palliative care patients, and caregivers by authors in the validated context of Hong Kong.[19]

Phase 2 Measurement

The questionnaire for family caregivers contains eight parts: (A) Their relationship with the elderly; (B) Healthcare experiences and attitudes, and preferences for EoLC; (C) Expectations of EoLC, (D) Advanced Care Planning experiences and attitudes; (E) awareness, experience, and attitudes toward Advance Directives (F) Ideal terminal/dying situations (preferences with respect to places of care and eventual death); (G) Quality of Life; and (H) Supplementary information on demographics, financial support for caregiving, bereavement experience, and self-rated health (personal profile). The contents are similar to the elderly survey version with slight changes in wording to include an item that measures the caregivers' understanding of the elderly's own perspective. Most of the questions are close-ended, while there are open-ended questions for the caregivers to express their own opinions.

For both the elderly and family surveys, there is a small ending section where interview staff can write their observation notes on respondents' emotions. Interviewers may also mark any words such as 'euthanasia' or 'hastened death' if these are mentioned during the conversations.[20]

Completion time for the interview is estimated to be 30-45 minutes. The RA will read out and explain all survey items one by one to the respondents to ensure the quality of the data collection. Furthermore, the respondents are not allowed to change their answer once the questions have been answered.

Patient and Public Involvement (PPI) statement

Potential barriers to study this population with PPI include the challenges of engaging the local elderly home management given that service providers are motivated to protect their residents

and may hesitate before to aid research, especially without formal ethical approval. The survey was developed after consultation with public representatives such as experienced staff members who work with the target population. We did not directly involve elderly at the initial stage of this study as we did not have any pre-established partnership with local RCHEs. The revision of the survey content based on pilot responses took the elderly participants' feedback into account. We radically revised the survey content by deleting some awareness items, changing the wording to make the current survey easier to use in formal study. More importantly, our plan to PPI develops as sharing findings in plain language with elderly homes and the general public in future. Their responses for our study findings will be invited, too.

Data Analysis

IBM SPSS and Mplus will be used for the statistical analyses. Descriptive analysis will first be conducted on demographics. Response frequencies for each measure will be tabulated and the corresponding proportions will be calculated by dividing the frequency by the number of respondents. We plan to apply Logistic Regression Analysis to investigate independent predictors of our outcomes of interests, for example, the participants' preference to have communication on ACP for their own terminal care. The associations of sociodemographic characteristics, frailty, depression, and functioning status with the outcomes will be analysed.

We will apply Kappa Statistics to examine paired results between the frail elderly and their family caregivers. Preferences for life sustaining treatment will be expressed in 3x2 tables and described in terms of percentage agreement and the kappa coefficient. The level of agreement will be described using indices such as 'agreement index' developed in literature on

treatment preferences. Where a caregiver could accurately interpret an elderly participant's preference in LST, whether that was for active treatment, against LST, or uncertain, they will gain a score of one. Thus, we will use a total score of 0 (no ability) through 8 (full ability) to know or estimate the family members' preferences in treatment for elderly residents who were at terminal stages from survey hypothetical scenarios. Combined agreement scores from all matched pairs of family caregivers and elderly respondents will represent overall agreement in the survey sample. Finally, we plan to calculate the association between elderly participants and family caregivers' characteristics and agreement scores through multiple linear regression.

ETHICS AND DISSEMINATION

The cross-sectional survey has been approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (IRB Reference number: UW 18-443). To respect the principles of human dignity and voluntary participation in the study, a comprehensive verbal explanation and a comprehensive information sheet will be provided to the participants (family caregivers and the frail elderly home residents) during the recruitment period, prior to the commencement of data collection. The purpose and procedure of the study as well as the risks and benefits of participation will be explained. Respondents will be encouraged to clarify any queries related to the study with the research staff. Oral consent will be obtained from elderly participants before commencing the individual interviews. For their family members, respondents can opt for either oral or written consent. Participation will be entirely voluntary, and respondents will be informed of their rights to withdraw or refuse to give information at any time without incurring penalties or deprivation of services.

There is a chance that these interviews may cause some stress for elderly participants beyond what is typical in their casual daily conversations given that as the survey covers death-related content. In the pilot interviews, signs of stress appeared occasionally as expected. Participants were asked whether they wanted to continue or not, and then their wishes were respected. Similarly, in the future interviews during the proposed study, the survey process will be paused in cases when participants are willing to continue despite stress to reduce potential harm to participants. The researchers will closely observe the reactions of the elderly participants. Additionally, relaxation techniques will be taught to the elderly participants on site as needed. This will be documented in our survey and referred to staff for appropriate follow-up. Moreover, positive answers to the item on suicidal ideation item and those with depression symptoms at the cut-off score of 2 or above will be brought to attention of the elderly home manager.[18]

The survey project has started in Nov. 1st, 2018 officially and aimed to complete by Oct. 30th, 2021. Our results of the proposed cross-sectional study will be reported with reference to the international statement in the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist for cross-sectional studies.[21] The findings will be disseminated through international conference presentations and peer-reviewed academic journal publications. Meanwhile, a report in plain language will be shared with our partner elderly homes. The evidence gathered from this study has the potential to benefit research on EoLC both locally and internationally, and to further inform practitioners on the desires and the EoLC needs of the frail elderly and their caregivers. It is very important to share the knowledge that we gain on the preferences of frail elderly home residents with professionals in healthcare sectors, such as physicians, direct service staff, and the larger community. Understanding their wishes can be a

great step towards developing better quality EoLC for the 8% of Hong Kong elderly population who reside in RCHEs.[22]

AUTHOR CONTRIBUTIONS

CL, PC, and BY conceptualized the survey design. BY and PC drafted the manuscript protocol. BY prepared the IRB application and the amendment from collaborative input. BY and XX conducted pilot survey interviews. BY and XX made the revision with CL. All the authors, including BY, XX, PC, NT, DC, FC, and CL, contributed to the development of the survey protocol and approved the final version of the manuscript.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

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ABSTRACT

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Methods and analysis: Surveys including ~~a~~ resident ~~version~~ and ~~a~~ family versions were developed based on the existing literature and our pilot interviews. The targeted participants are 400 frail elderly home residents (aged ≥65 years old) and 200 family caregivers ~~as matched with elderly respondents~~. Purposive sampling will be used as each elderly home will help to recruit five to fifteen elderly participants for the study. Descriptive analysis and modeling will be used to examine ~~awareness,~~ preferences on EoLC~~,~~ and related factors, as well as to compare resident responses with those of their family caregivers.

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INTRODUCTION

End-of-life-care (EoLC) attitudes have ~~attracted~~ increasingly attracted attention in peer-reviewed journals.[1-~~4, 10, 11,~~ 12]- The literature indicates that EoLC for terminally ill patients can include many challenges, for example, access to services, quality of care, awareness, attitudes, communication, and decision making.[4] Advance care planning (ACP) and advance directives (ADs) have been promoted in order to discover patient attitudes towards their EoLC,[5] with the benevolent intention that these processes help to honour their wishes or preferences for a good death. An AD is one of the potential outcomes of participation in ACP. Both ADs and ACP involve the patients' understanding of life-sustaining treatment (LST).[6] Several studies have demonstrated that the ~~general public~~ awareness of ~~Advance Directives (AD)~~AD ~~wa~~is low among Chinese population. [1-3, 5]~~[1, 10, 11, Lee, 2014]~~ Moreover, a recent systematic review~~[12] that~~ summari~~sz~~ed 107 EoLC studies in Hong Kong in the past decade reported ~~low awareness of~~ a primary focus on ~~Advanced Care Planning (~~AD ~~-~~rather than ACP.[4] Studies of~~n~~ Chinese family attitudes towards ACP present~~have~~ mixed findings according to Lee's review in 2014.[5] ~~O~~Therefore, our study aims to ~~study~~investigate EoLC preferences and relevant factors, such as ACP and AD awareness, preferences concerning~~for~~ LST, decision-making, and preferred place of death, by conducting original surveys with ~~CP)~~ ~~among~~ frail elderly people and their family caregivers. ~~Potential barriers to research include the challenges of engaging elderly homes given that service providers are motivated to protect their residents and may hesitate before to aid researchers.~~

By definition, frailty refers to athe vulnerable state in which there is an increased risk of hospitaliszation, deterioration in functioning, and mortality.[7] The frail elderly arepeople are particularly under studied, and thus their voices have rarelynot been sufficiently heard amongby academics, politicians, or and athe wider public audience. Our study will help to bridge this knowledge gap. Even tThough we found the most recent report on prevalence of Hong Kong general public preferences regarding EoLC and preferred place of death,[1, 813] these results were generated from telephone landline surveys, which did not reach the frail elderly population living in RCHE. The public percentage of their studied participants who joinanswered the brief home phone interview calls may not represent the views of frail elderly people home residents on these sensitive topics. The landline phone calls could not reach the frail elderly population living in residential care homes for the elderly (RCHEs), including nursing homes, care and attention homes, and other types of homes that provide comprehensive care for dependent people.[9] Our study will help to bridge this knowledge gap. Face-to-face interviews with the frail elderly will help to gain a better understanding of their attitudes.

The present study is significant as the population of Hong Kong (HK) ranks top in life expectancy around the globe, and with the percentage of its ageing population continues to risinge.[1,9] The government officially projects that the percentage of elderly residents aged 65 and above will keep growing from over one million to 2.61 million in 2058 (36% of the Hong Kong population).[1, 102] This is much higher than the global estimate of the elderly population (21.1% percent in 2050).[113] At present, the demands for residential elderly care services in Hong Kong remain overwhelming.. Though a total of 32,418 places were offered in Residential Care Homes for Elderly (RCHE), as reported by the Social Welfare Department of HK in March

~~2018, the June 2018 update of the central waiting list contains 39,209 applicants for subsidized residential care facilities.[4, 5] The~~ with average waiting time ~~to enter a residential care setting i~~as long as 24 months for admission.[12~~6~~] ——Due to priority consideration~~s for waitlisted applicants~~, frailty is one of the primary characteristics taken into account for elderly being admitted to ~~Residential Care Homes for the elderly (~~Hong Kong RCHEs~~)~~ ~~settings~~. ~~By definition, frailty refers to the vulnerable state in which there is an increased risk of hospitalization, deterioration in functioning, and mortality.[7] Additionally, there is a significant interaction effect reported between frailty and depression among the HK elderly in terms of their subjective health.[8] Prevalence of depression among the elderly Chinese of HK is reported to be the highest (12%) in long-term care institutions as compared to other residential settings, as reported in a study with a total sample of 56,000.[9] According to their cohort study findings, depressive symptoms independently predicted the risk of suicide.~~ Therefore, it is critically important to study the elderly ~~people~~home residents with ~~relatively high~~ pre-frail or frail~~ty~~ statuses as they are more likely to receive ~~toward their end-of-life care (~~EoLC~~)~~ in residential homes.[9] ~~Potential barriers to study this population include the challenges of engaging the local elderly homes given that service providers are motivated to protect their residents and may hesitate before to aid researchers.~~

Meanwhile, ~~it is urgent to update our~~ knowledge about the region must be urgently updated as the only studies on EoLC among elderly home residents in Hong Kong were conducted roughly ten~~10~~ years ago.[4, 6, 12~~, 14~~] ~~The influential factors for their preferences h~~Hypothesising those factors that influence~~zed~~ their preferences from the existing literature enables us to explore additional possible predictors. ~~The socio-economic predictors of higher~~

awareness of EoLC and preference to die outside of hospitals were clearly lacking in previous studies.[14] The present study will use a comprehensive design to explore the under-researched topic of EoLC preferences of an under-studied neglected population: the frail elderly home residents. Within the familiesy context, caregivers' attitudes are also crucial, as they play a significant role as surrogate decision-makers in the future circumstance decision making in the case that of an elderly family member, who does not have an AD or ACP, losinges the capacity to make decisions on their own and does not have an AD. A recent systematic review by Wang and Chan shows[12] that family caregivers in HK have been an insufficiently studied population in research.Families often find making EoLC decisions very stressful. Those with problematic family dynamics tend to opt for aggressive treatment.[137, 148] Their findings highlight the importance of communication rather than assuming the families know what the patients want regarding their EoLC. It is unknown whether the family situation of HK's frail elderly is similar to previous research elsewhere or not. The systematic review by Wang and Chan shows that family caregivers in Hong Kong have also been an insufficiently studied population in research. [412] Thus, it is worth further investigation of caregiver's attitudes, and so we include this comparative perspective this in our analysis to compare the perspectives is worthwhile.

Understanding this population is necessary in order to provide better quality of elderly care and to develop new services for unmet needs based on existing system strengths, particularly in facing the rapid ageing trend. This is consistent with the World Health Organization's (WHO) initiative to build an age-friendly environment.[113] The need to enhance the quality of EoLC in RCHEs, dying is recognized our survey findings will be a helpful reference to further identifying some directions for public education and other interventions in

order to meet the needs of ~~in~~ Hong Kong's frail elderly home residents. ~~Before developing new services, the first step is to understand the preferences of the public, especially elderly people. The current study could lend support for feasible possibilities of future intervention research. In addition, our comprehensive survey includes important variables such as depression, pain, Activities of Daily Living (ADL), suicidal ideation, and frailty, which will definitely enrich the research area.[2, 6-15] The implications from these findings will help the government to improve the allocation of resources in developing EoLC services. Researchers will be able~~ Our survey findings will be helpful reference to further identify future directions for public education and ~~other types of intervention to meet the EoLC needs of HK's frail elderly citizens.~~

~~Within the family context, caregivers' attitudes are also crucial, as they play a significant role in future decision making in the case that an elderly family member loses the capacity to make decisions on their own and does not have an AD. A recent systematic review by Wang and Chan shows[12] that family caregivers in HK have been an insufficiently studied population in research. The dyad questionnaire in the current study is designed to match the caregiver's understanding/expectation of the elderly family member's preference and the elderly's own wish as expressed to research staff directly. It aims to be elderly-centered. Referring to a recent dyad study,[16] agreement between caregiver's expectation and the elderly's own wish is low or at best moderate. Caregiver rating on uncertainty is high. Families often find making EoLC decisions very stressful. Those with problematic family dynamics tend to opt for aggressive treatment.[17, 18] Their findings highlight the importance of communication rather than assuming the families know what the patients want regarding their EoLC. It is unknown whether~~

~~the family situation of HK's frail elderly is similar to previous research elsewhere or not. Thus, further investigation of this in our analysis to compare the perspectives is worthwhile.~~

Research questions

Phase 1: Survey of ~~E~~elderly home residents ~~survey~~

~~i)~~ What is the level of awareness of such terms ~~such~~ as living will, ~~EoLC~~AD, or ACP~~,~~ ~~and life-sustaining treatment~~ in Hong Kong among the frail elderly ~~and their family caregivers?~~

~~ii) What is the elderly's personal exposure to such terms?~~

~~iii) What are~~ and what are their preferences with regard to decision-making, LST ~~life-sustaining treatment~~, AD, ACP, EoLC, and preferred place of death?

~~iv) Are there any demographic and personal features related to preference and level of awareness?~~ Phase 2: ~~C~~Family caregiver survey

What is the level of awareness of terms such as living will, AD, ACP in Hong Kong among their family caregivers

~~v) Is there any relationship between the elderly's expression of preferences~~ and what are their ~~caregiver's~~ ~~expectation~~ attitudes of ~~on~~ elderly family member~~'~~s' preferences?

~~**Outcomes**~~

~~i) Primary outcome: The frail elderly preferred place of death.~~

~~ii) Secondary outcomes: The frail elderly's level of awareness and preferences with regard to AD, ACP, and EoLC; the elderly and their family caregivers' dyad awareness of these terms and preferences, as well as the agreement betweenon elderly's preferences, and family caregivers' awareness of these terms.~~

METHODS AND ANALYSIS

Design

~~A~~ Prior to the main cross-sectional study, a pilot questionnaire has been completed on one site with~~of~~ a sample of 12 participants in an ~~elderly home~~RCHE ~~prior to the main study~~. ~~F~~The feasibility of the survey content was assessed. During our pilot survey interviews, we found the majority (10 out of 12 ~~participants~~) of participants who agreed to join the study were happy or felt it was acceptable to discuss EoLC issues with us, while the remaining two elderly lost interests or refused to continue in the middle of the interviews. Withdrawal was respected. Afterwards, no severe distress was reported or observed. Similarly, the existing literature shows that elderly people in Hong Kong facilities are willing to talk about issues related to death and dying.[12~~6~~] ~~Most of the participants (11 out of 12) in our pilot were considered as belonging to either the category of Pre-frail or Frail.~~ This offers our survey the advantage of gaining first-hand knowledge about the elderly's preferences and experiences. In the pilot ~~studies~~, only one participant out of the 12 elderly had heard of AD or~~and~~ ACP before our interviews. This low level of awareness is consistent with ~~the report of~~ earlier surveys~~, where~~ that reported that 96% and 85.7% of people surveyed had never heard of AD ~~in Chu's study and 85.7% in Chung's study~~.-[1, 8~~13~~]

We conducted four phone interviews with family caregivers as a pilot ~~survey~~for the family version of the survey. Three ~~out~~ of the four interviews were completed, but the only dropout occurred in the middle when she suspected that our interview was ~~trying~~actually an attempt to sell her something ~~dying plan~~. Feasibility and acceptance of our survey appears high for Chinese frail elderly home residents and family caregivers in Hong Kong.

——We have made modifications to the version for the ~~on~~ elderly ~~version~~ to shorten the questionnaire to reduce burden of participation. We have added explanations of~~n~~ ACP and AD in plain language, so that it is easier for lay participants to understand. We have provided~~given~~ more choices on why participants want to or not want to consider initiating ACP ~~and~~ or an AD based on pilot findings.

Outcomes

i) Phase 1 Primary outcome: ~~The frail elderly p~~Preferences of the frail elderly on ACP.

ii) Phase 1 Secondary outcomes: The frail elderly's level of awareness and preferences with regard to ~~life sustaining treatment~~LST, decision-making, AD, preferred place of death, and quality of life.~~;~~

iii) Phase 2 Primary outcome: Level of agreement between ~~their~~ family caregivers' preferences and those of elderly's ~~preferences~~ on ACP for elderly home residents.

iv) Phase 2 Secondary outcomes: ~~f~~Family caregivers' awareness of these terms and preferences with regard to LST, decision-making, ACP, AD, and preferred place of death~~, as well as the agreement between elderly's preferences, and family caregivers'~~.

Participants

Phase 1 Frail elderly home residents

The inclusion criteria for the frail elderly participants are as follows:

i) At least 65 years of age;

ii) Chinese in elderly ~~HK~~ homes who can speak and understand either Cantonese or Mandarin;

iii) Either ~~P~~pre-frail or ~~f~~~~F~~frail (rating 1-5 on FRAIL) ~~-~~ [15]

The exclusion criteria for frail elderly participants are:

i) Cognitive impairment (scoring 5 or below on the a~~A~~bbreviated m~~M~~ental t~~T~~est [AMT]).[16~~25~~] To screen for ineligibility due to cognitive impairment, the Chinese AMT will be used.

ii) Communication problems due to functional impairment (for example, deafness or~~,~~ aphasia).

Phase 2 Family caregivers

The inclusion criteria for family caregiver participants are as follows

i) Hong Kong Chinese adults (18 years of age or above) who can speak and understand Cantonese or Mandarin.

The exclusion criteria for family caregiver participants are:

(i) Communication problems due to functional (deafness, aphasia) or intellectual impairment.

Recruitment

We plan to partner with 32 elderly homes with an average of 12 residents from each home. Under the most conservative scenario (assuming the true proportion is 50%), a sample of 384 elderly residents will be required to give a 95% confidence interval for the proportion of people who would prefer to have -communication on ACP ~~dying in elderly homes,~~ with a margin of error of 5%. To cater for inter-correlation within residents in the same home, we assume ICC to be 0.05. We will expect to interview 400 elderly in order to collect their responses to the survey in the first phase. Assuming that around half of these elderly people will have family caregivers willing to join the study, 200 family caregivers will be interviewed in the second phase.

——Using a purposive sampling method, we plan to select elderly homes in all main regions of Hong Kong (Hong Kong Island, Kowloon, and the New Territories) by sending out invitations via mail and by convenient professional networks. The managers of the elderly care homes will be approached via phone calls and asked permission to let us interview their elderly residents. ~~Written invitations will be sent to family caregivers with requests for information release of their elderly relatives.~~ The elderly residents in the homes will be invited in person to

participate in face-to-face survey interviews. The family caregivers can ~~call to schedule~~ choose to join caregiver interviews ~~(also optional)~~ via either face-to-face or via phone survey with our research staff at a time and place ~~convenient to both~~ as mutually agreed. ~~Each matching pair will be included in our pool of studied dyads.~~

——The facility staff will introduce us to the elderly candidates. There will be no monetary incentives offered to either the participants or the agencies involved. During the recruitment process, the research assistant (RA) will explain the study to the potential participants either in a private room (bedside/chairside) or in a corner of a common room to protect privacy. After seeking oral ~~or implicit~~ consent from residents to participate, the RA will administer the AMT and the five-item Frailty scale to screen out ineligible ~~subject~~ones based on our exclusion criteria. The ~~Co-I or the R~~RA ~~-~~will then conduct a face-to-face individual interview with the participant using our designed questionnaire. Trained RAs will collect data during the interviews on either paper or tablet form, depending on the ~~interviewer and~~ Internet availability. Participants therefore have the convenient option to fill out the surveys on their mobile smartphones or tablets.~~[26]~~ Paper-based surveys will serve as a backup option.

Survey interviews

——A structured questionnaire (one version for the frail elderly and the other version their family caregivers) has been developed based on the objectives of the current study and with reference to recent publication on similar topics.[1-3, ~~10, 11~~] Additional scales were integrated to design this comprehensive survey study. The authors ~~PI and the Co-Is~~ ascertained face validity based on

literature and research experience in the area. The Chinese questionnaires have been viewed by a panel of six Hong Kong local experts, including one geriatric doctor, one clinical psychologist, two nurses, and two social workers. The first elderly questionnaire has been pilot tested on one site with a sample of 12 elderly Chinese to test for feasibility. We then revised the survey in preparation for the main study. After that the pilot test, the experts were invited to judge the content validity of the questions for the second time as the questionnaires were developed. The content validity index was calculated as excellent (CVI/AVR = 0.87 for elderly and 0.98 for caregiver survey).

Phase 1 Measurement

The ~~Abbreviated Mental Test (~~AMT~~)~~ and FRAIL screening tools will be applied to select our participants. The interview for the frail elderly will be conducted if they are deemed eligible. The questionnaire contains seven parts: (A) Demographics and functioning (personal profile); (B) Healthcare experiences and attitude; (C) Expectations of EoLC, (D) Advanced Care Planning experience and attitude; (E) Advance Directives awareness, experience, and attitude (F) Ideal terminal/death environment (preferences on places of care and eventual death); and (G) Quality of Life.

(A) Demographic information including age, sex, educational level, marital status, religion, financial source, type of nursing home, family members, ~~previous living arrangement,~~ self-reported health and pain severity, and bereavement experience, etc., will be collected. To assess daily functioning, frailty, depressive symptoms, and suicidal ideation, we will use the following respective scales, 10-item Barthel Index on ADL,[178] 5-item FRAIL,[159~~-21~~] Geriatric Depression Scale GDS-4, and a single-item suicidal ideation assessment.[1822] ~~If the family and the staff in residential care settings give permission for such information to be released, we~~

~~would obtain the most recent records from their files. The records must be up-to-date within the past 6 months. If not, we will conduct our own collection.~~

(B) The participants will be asked to share their experience of and attitude toward life sustaining treatment and previous hospitali~~s~~zation according to questions we have devised.

(C) The participants will be asked to rate their opinions on decision making with regard to LST ~~life-sustaining treatment~~ in a hypothetical dying scenario, and their attitudes on quality of life at the end of life. The hypothetical dying scenario will be described in one phrase as "becoming seriously ill but with no cure available" for themselves.

(D) The participants will be asked about their awareness and experience or participation in ACP, their attitudes and preferred communication with others, as well as their reasons for rejecting the idea of ACP.

(E) Participants will be asked about their awareness of a living will and AD, and about their current ~~process~~consideration in formulating their written preferences on medical decisions and AD. The reasons behind their choices and the persons who introduced these topics to them will also be explored.

(F) The participants will be asked to rate their opinions on their hypothetical dying situation, i.e., the ideal places of their terminal care and death. They will be asked about their preferences regarding dying alone or having certain persons around them during their own eventual death.

(G) The McGill Quality of Life (M-QoL-HK) questionnaire will be used to measure Quality of Life among Hong Kong adults. Through a ten-point Likert Scale of 17 items, M-QoL measures four dimensions, including physical health, psychological/mental health, spiritual wellbeing, and overall quality of life. The items in M-QoL are considered applicable to both

elderly, palliative care patients, and caregivers by authors in the validated context of Hong Kong.[19~~23~~]

Phase 2 Measurement

The questionnaire for family caregivers contains eight parts: (A) Their relationship with the elderly; (B) Healthcare experiences and attitudes, and preferences for EoLC; (C) Expectations of EoLC, (D) Advanced Care Planning experiences and attitudes; (E) awareness, experience, and attitudes toward Advance Directives (F) Ideal terminal/dying situations (preferences with respect to places of care and eventual death); (G) Quality of Life; and (H) Supplementary information on demographics, financial support for caregiving, bereavement experience, and self-rated health (personal profile). The contents are similar to the elderly survey version with slight changes in wording to include an item that measures the caregivers' understanding of the elderly's own perspective. Most of the questions are close-ended, while there are open-ended questions ~~options~~ for the caregivers to express their own opinions.

For both the elderly and family surveys, there is a small ending section where interview staff can write their observation notes on respondents' emotions. Interviewers may also mark any words such as 'euthanasia' or 'hastened death' if these are mentioned during the conversations.[204]

Completion time for the interview is estimated to be 30-45 minutes. The RA ~~trained research assistants~~ will read out and explain all survey items one by one to the respondents to ensure the quality of the data collection. Furthermore, the respondents are not allowed to change their answer once the questions have been answered.

Patient and Public Involvement (PPI) statement

Potential barriers to study this population with PPI include the challenges of engaging the local elderly home management given that service providers are motivated to protect their residents and may hesitate before to aid research, especially without formal ethical approval. The survey was developed after consultation with public representatives such as experienced staff members who work with the target population. We did not directly in~~clude Patient and Public In~~volve ~~ment (PPI)~~elderly at the initial stage of~~in~~ this study as we did not have any pre-established partnership with local RCHEs. ~~However, the survey was developed after consultation with public representatives such as experienced staff members who work with the target population.~~ The revision of the survey content based on pilot responses took the elderly participants'~~ir~~ feedback ~~comments~~ into account. We radically revised the survey content by deleting some awareness items, changing the wording to make the current survey easier to use in formal study. More importantly, our plan to PPI develops as sharing findings in plain language with elderly homes and the general public in future. Their responses for our study findings will be invited, too.

A pilot questionnaire has been completed on one site of a sample of 12 in an elderly home prior to the main study. Feasibility of the survey content was assessed. During our pilot survey interviews, we found the majority (10 out of 12 participants) who agreed to join the study were happy or felt it was acceptable to discuss EoLC issues with us, while the remaining 2 expressed discomfort or refused to continue in the middle of the conversation. Similarly, existing literature shows that elderly people in Hong Kong facilities are willing to talk about issues related to death and dying.[6] Most of the participants (11 out of 12) in our pilot were considered as belonging to either the category of Pre-frail or Frail. This offers our survey the advantage of gaining first-hand knowledge about the elderly's preferences and experiences.

Furthermore, we plan to share our findings in the form of an explanation after the interview so that participants know where to obtain further details as needed. This survey study itself can increase public awareness of EoLC among the elderly. In the pilot studies, only one participant out of the 12 elderly had heard of AD and ACP before our interviews. This low level of awareness is consistent with the report of earlier surveys, where 96% never heard of AD in Chu's study and 85.7% in Chung's study. [1, 13]

We plan to partner with 32 elderly homes with an average of 12 residents from each home. Under the most conservative scenario (assuming the true proportion is 50%), a sample of 384 elderly residents will be required to give a 95% confidence interval for the proportion of people who would prefer dying in elderly homes, with a margin of error of 5%. To cater for inter-correlation within residents in the same home, we assume ICC to be 0.05. We will expect to interview 400 elderly in order to collect their responses to the survey. Assuming that around half

of these elderly people will have family caregivers to join the study, 200 family caregivers will be interviewed.

Using a purposive sampling method, we plan to select elderly homes in all main regions of HK (Hong Kong Island, Kowloon, and the New Territories) by sending out invitations via mail and by convenient professional networks. The managers of the elderly care homes will be approached via phone calls and asked permission to let us interview their elderly residents. Written invitations will be sent to family caregivers with requests for information release of their elderly relatives. The elderly residents in the homes will be invited in person to participate in face-to-face survey interviews. The family caregivers can call to schedule caregiver interviews (also optional) with our research staff at a time and place convenient to both as mutually agreed. Each matching pair will be included in our pool of studied dyads.

The facility staff will introduce us to the elderly candidates. There will be no monetary incentives offered to either the participants or the agencies involved. During the recruitment process, the research assistant (RA) will explain the study to the potential participants either in a private room (bedside/chairside) or in a corner of a common room to protect privacy. After seeking oral or implicit consent from residents to participate, the RA will administer the AMT and the five-item Frailty scale to screen out ineligible subjects based on our exclusion criteria. The Co-I or the RA will then conduct a face-to-face individual interview with the participant using our designed questionnaire. Trained RAs will collect data during the interviews on either paper or tablet form, depending on the interviewer and Internet availability. Participants

~~therefore have the convenient option to fill out the surveys on their mobile smartphones or tablets.[26] Paper-based surveys will serve as a backup option.~~ ~~Missing items will be noted as 999 automatically in the database.~~

Data Analysis

IBM SPSS ~~version 25~~ and Mplus will be used for the statistical analyses. Descriptive analysis will first be conducted on demographics. Response frequencies for each measure will be tabulated and the corresponding proportions will be calculated by dividing the frequency by the number of respondents. We plan to apply Logistic Regression Analysis to investigate independent predictors of our outcomes of interests, for example, the participants' preference to ~~die in elderly residential homes~~have communication on ACP for their own terminal care. The associations of sociodemographic characteristics, frailty, depression, and functioning status with the outcomes will be analy~~z~~s~~ed~~.

We will apply Kappa Statistics to examine paired results between the frail elderly and their family caregivers. Preferences for life sustaining treatment will be expressed in 3x2 tables and described in terms of percentage agreement and the kappa coefficient. The level of agreement will be described using indices such as 'agreement index' developed in literature on treatment preferences. Where a caregiver could accurately interpret an elderly person's preference in LST, whether that was for active treatment, against LST, or uncertain, they will gain a score of one. Thus, we will use a total score of 0 (no ability) through 8 (full ability) to know or estimate the

family members' preferences in treatment for elderly residents who were at terminal stages from survey hypothetical scenarios. Combined agreement scores from all matched pairs of family caregivers and elderly respondents will represent overall agreement in the survey sample. Finally, we plan to calculate the association between elderly participants and family caregivers' characteristics and agreement scores through multiple linear regression.

ETHICS AND DISSEMINATION

The cross-sectional survey has been approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (IRB Reference number: UW 18-443). To respect the principles of human dignity and voluntary participation in the study, a comprehensive verbal explanation and a comprehensive information sheet will be provided to the participants (family caregivers and the frail elderly home residents) during the recruitment period, prior to the commencement of data collection. The purpose and procedure of the study as well as the risks and benefits of participation will be explained. Respondents will be encouraged to clarify any queries related to the study with the research staff. Oral consent will be obtained from elderly participants before commencing the individual interviews. For their family members, respondents can opt for either oral or written consent. Participation will be entirely voluntary, and respondents will be informed of their rights to withdraw or refuse to give information at any time without incurring penalties or deprivation of services.

There is a chance that these interviews may cause some stress for elderly participants beyond what is typical in their casual daily conversations given that as the survey covers death-related

content. In the pilot interviews, signs of stress appeared occasionally as expected. Participants were asked whether they wanted to continue or not, and then their wishes were respected. Similarly, in the future interviews during the proposed study, the survey process will be paused in cases when participants are willing to continue despite stress to reduce potential harm to participants. The ~~RA and the Co-I~~ researchers will closely observe the reactions of the elderly participants. Additionally, relaxation techniques will be taught to the elderly participants on site as needed. This will be documented in our survey and referred to staff for appropriate follow-up. Moreover, positive answers to the item on suicidal ideation item and those with depression symptoms at the cutoff score of 2 or above will be brought to attention of the elderly home managers~~staff~~.[18~~23~~]

The survey project has~~study~~ started in Nov. 1st, 2018 officially and aimed to complete by Oct. 30th, 2021. Our results of the proposed cross-sectional study will be reported with reference to the international statement in the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist for cross-sectional studies.[2~~7~~1] The findings will be disseminated through international conference presentations and peer-reviewed academic journal publications. Meanwhile, a report in plain language will be shared with our partner elderly homes. The evidence gathered from this study has the potential to benefit research on EoLC both locally and internationally, and to further inform practitioners on the desires and the EoLC needs of the frail elderly and their caregivers. It is very important to share the knowledge that we gain on the preferences of frail elderly home residents with professionals in healthcare sectors, such as physicians, direct service staff, and the larger community. Understanding their

wishes can be a great step towards developing better quality EoLC for the 8% of Hong Kong elderly population who reside in RCHEs. [22]

AUTHOR CONTRIBUTIONS

CL, PC, and BY conceptualized the survey design. BY and PC drafted the manuscript protocol. BY prepared the IRB application and the amendment with collaborative input. BY and XX conducted pilot survey interviews. BY and XX made the revision with CL. All the authors, including BY, XX, PC, NT, DC, FC, and CL, contributed to the development of the survey protocol ~~with revisions~~ and approved the final version of the manuscript.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

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Preferences for End-of-Life Care: A Study Protocol for a Cross-sectional Survey of Chinese Frail Elderly Home Residents in Hong Kong

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ABSTRACT

Introduction: Existing literature on attitudes toward end-of-life care (EoLC) covers the general public but has little information on the frail elderly population. The aim of the current study is to investigate the preferences of Chinese frail elderly home residents with respect to EoLC by conducting cross-sectional surveys.

Methods and analysis: Surveys, including resident and family versions, were developed based on the existing literature and our pilot interviews. The targeted participants were 400 frail elderly home residents (aged ≥65 years old) and 200 family caregivers. Purposive sampling will be used as each elderly home will help to recruit 5 to 15 elderly participants for the study. Descriptive analysis and modelling will be used to examine preferences on EoLC and related factors, as well as to compare the responses of elderly home residents with those of their family caregivers.

Ethics and dissemination: The cross-sectional survey has obtained IRB approval. Confidentiality and safety issues will be carefully observed. The results of the study will be disseminated through international conferences, peer-reviewed academic journal publications, and a report in plain language to be shared with elderly residential homes.

Strengths and limitations of this study:

- Survey versions were developed to inquire into the preference of both the frail elderly home residents and family caregivers.
- For the first time, surveys on elderly people's attitudes towards EoLC cover all main areas of Hong Kong.
- The cross-sectional design of this study cannot conclude causality.
- Participants with communication problems (i.e., deafness or aphasia) were excluded due

to the nature of the data collection method.

INTRODUCTION

End-of-life care (EoLC) attitudes have increasingly attracted attention in peer-reviewed journals.[1-4] The literature indicates that EoLC for terminally ill patients can include many challenges, for example, access to services, quality of care, awareness, attitudes, communication, and decision making.[4] Advance care planning (ACP) and advance directives (ADs) have been promoted in order to discover patient attitudes towards their EoLC,[5] with the benevolent intention that these processes help to honour their wishes or preferences for a good death. An AD is one of the potential outcomes of participation in ACP. Both ADs and ACP involve the patients' understanding of life-sustaining treatment (LST).[6] Several studies have demonstrated that the awareness of AD is low in Chinese populations.[1-3, 5] Moreover, a recent systematic review summarised 107 EoLC studies in Hong Kong in the past decade reported a primary focus on AD rather than ACP.[4] Studies of Chinese family attitudes towards ACP present mixed findings according to Lee's review in 2014.[5] Therefore, our study aims to investigate the preferences of Chinese frail elderly home residents with respect to EoLC. We explore their preferences along with relevant factors, such as ACP and AD awareness, preferences concerning LST, decision-making, and preferred place of death, by conducting original surveys with frail elderly home residents and their family caregivers.

By definition, frailty refers to a vulnerable state in which there is an increased risk of hospitalisation, deterioration in functioning, and mortality.[7] Frail elderly people are particularly understudied, and thus their voices have rarely been heard by academics, politicians, or the wider public. Though we found the most recent report on the prevalence of Hong Kong

general public preferences regarding EoLC and preferred place of death,[1, 8] these results were generated from telephone landline surveys. The public participants who joined the brief phone interview may not represent the views of frail elderly home residents on these sensitive topics. The landline phone calls could not reach the frail elderly population living in residential care homes for the elderly (RCHEs), including nursing homes, care and attention homes, and other types of homes that provide comprehensive care for dependent people.[9] Our study will help to bridge this knowledge gap. Face-to-face interviews with frail elderly home residents will help to gain a better understanding of their attitudes.

The present study is significant as the population of Hong Kong ranks top in life expectancy around the globe, and the percentage of its ageing population is rising.[1, 9] The government officially projects that the percentage of elderly residents aged 65 and above will continue to grow from over one million to 2.61 million in 2058 (36% of the Hong Kong population).[1, 10] This is much higher than estimates of the global elderly population (21.1% in 2050).[11] At present, the demands for residential elderly care services in Hong Kong remain overwhelming, with average waiting time as long as 24 months for admission.[12] Due to priority considerations, frailty is one of the primary characteristics taken into account for elderly people being admitted to Hong Kong RCHEs.[9] Therefore, it is critically important to study the elderly home residents with pre-frail or frail statuses as they are most likely to receive EoLC in residential homes.[9]

Meanwhile, knowledge about the region must be urgently updated as the only studies on EoLC among elderly home residents in Hong Kong were conducted roughly ten years ago.[4, 6, 12] Hypothesising those factors that influence their preferences from the existing literature enables us to explore additional possible predictors. The present study will use a comprehensive

design to explore the under-researched topic of EoLC preferences of an understudied population: frail elderly home residents. Within families, caregivers' attitudes are also crucial, as they play a significant role as surrogate decision-makers in the future circumstance of an elderly family member, who does not have an AD or ACP, losing the capacity to make decisions on their own. Families often find making EoLC decisions very stressful.[13, 14] The systematic review by Wang and Chan shows that family caregivers in Hong Kong have also been an insufficiently studied population.[4] Thus, it is worth further investigation of caregiver's attitudes, and so we include this comparative perspective in our analysis. This is consistent with the World Health Organization's initiative to build an age-friendly environment.[11] To enhance the quality of EoLC in RCHEs, our survey findings will be a helpful reference to further identifying some directions for public education and other interventions in order to meet the needs of Hong Kong's frail elderly home residents.

Research questions

Phase 1: Survey of elderly home residents

What is the level of awareness of such terms as living will, AD, or ACP in Hong Kong among the frail elderly people, and what are their preferences with regard to ACP, decision-making, LST, AD, EoLC, and preferred place of death?

Phase 2: Family caregiver survey

What is the level of awareness of such terms such as living will, AD, or ACP in Hong Kong among family caregivers, and what are their attitudes of elderly family members' preferences?

METHODS AND ANALYSIS

Design

Prior to the main cross-sectional study, a pilot questionnaire has been completed on one site with a sample of 12 participants in an RCHE. The feasibility of the survey content was assessed. During our pilot survey interviews, we found the majority (10 out of 12) of participants who agreed to join the study were happy or felt it was acceptable to discuss EoLC issues with us, while the remaining two participants lost interest or refused to continue in the middle of the interviews, and their withdrawal was respected. Afterwards, no severe distress was reported or observed. Similarly, the existing literature shows that elderly people in Hong Kong facilities are willing to talk about issues related to death and dying.[12] This offers our survey the advantage of gaining first-hand knowledge about the elderly people's preferences and experiences. In the pilot, only one participant out of the 12 participants had heard of AD or ACP before our interviews. This low level of awareness is consistent with earlier surveys that reported that 96% and 85.7% of people surveyed had never heard of AD.[1,8]

We conducted four phone interviews with family caregivers as a pilot for the family version of the survey. Three of the four interviews were completed, and the only dropout occurred part way through an interview when the participant incorrectly thought that our interview was an attempt to sell her something. Feasibility and acceptance of our survey appear high among frail elderly home residents and family caregivers in Hong Kong. We have made

modifications to the version for the elderly person to shorten the questionnaire to reduce the burden of participation. We have added explanations of ACP and AD in plain language so that it is easier for lay participants to understand. We have provided more choices on why participants do or do not want to consider initiating ACP or an AD based on the pilot findings.

Outcomes

i) Phase 1 Primary outcome: Preferences of the frail elderly person on ACP.

ii) Phase 1 Secondary outcomes: The frail elderly person's level of awareness and preferences with regard to LST, decision-making, AD, preferred place of death, and quality of life.

iii) Phase 2 Primary outcome: Level of agreement between Family caregivers' preferences and those of elderly's on ACP for elderly home residents.

iv) Phase 2 Secondary outcomes: Family caregivers' awareness of these terms and preferences with regard to LST, decision-making, ACP, AD, and preferred place of death.

Participants

Phase 1 Frail elderly home residents

The inclusion criteria for the frail elderly participants are as follows:

i) At least 65 years of age;

ii) Chinese in elderly homes who can speak and understand either Cantonese or Mandarin;

iii) Either pre-frail or frail status (rating 1-5 on FRAIL).[15]

The exclusion criteria for frail elderly participants are:

i) Cognitive impairment (scoring five or below on the abbreviated mental test [AMT]).[16] To screen for ineligibility due to cognitive impairment, the Chinese AMT will be used.

ii) Communication problems due to functional impairment (for example, deafness or aphasia).

Phase 2 Family caregivers

The inclusion criteria for family caregiver participants are as follows

i) Hong Kong Chinese adults (18 years of age or above) who can speak and understand Cantonese or Mandarin.

The exclusion criteria for family caregiver participants are:

(i) Communication problems due to functional (deafness or aphasia) or intellectual impairment.

Recruitment

We plan to partner with 32 local elderly homes with an average of 12 residents from each home. Under the most conservative scenario (assuming the true proportion is 50%), a sample of 384 elderly residents will be required to give a 95% confidence interval for the proportion of people who would prefer to have communication on ACP with a margin of error of 5%. To cater for inter-correlation within residents in the same home, we assume ICC to be 0.05. We will expect to interview 400 elderly participants in order to collect their responses to the survey in the first phase. Assuming that around half of these elderly people will have family caregivers willing to join the study, 200 family caregivers will be interviewed in the second phase.

Using a purposive sampling method, we plan to select elderly homes in all main regions of Hong Kong (Hong Kong Island, Kowloon, and the New Territories) by sending out invitations via mail and by convenient professional networks. The managers of the elderly care homes will be approached via phone calls and asked permission to let us interview their elderly residents. The elderly residents in the homes will be invited in-person to participate in face-to-face survey interviews. The family caregivers can choose to join caregiver interviews via either face-to-face or via phone survey with our research staff at a time convenient as mutually agreed.

The facility staff will introduce us to the elderly candidates. There will be no monetary incentives offered to either the participants or the agencies involved. During the recruitment process, the research assistant (RA) will explain the study to the potential participants either in a private room (bedside/chairside) or in the corner of a common room to protect privacy. After seeking oral consent from residents to participate, the RA will administer the AMT and the five-item Frailty scale to screen out ineligible ones based on our exclusion criteria. The RA will then conduct an individual face-to-face interview with the participant using our designed questionnaire. Trained RAs will collect data during the interviews on either paper or digital form, depending on Internet availability. Digital devices (i.e., smartphones or tablets) for accessing the digital survey will be operated by the research staff during the interviews with the participants, and paper-based surveys will serve as a backup option.

Survey interviews

A structured questionnaire (one version for the frail elderly and the other version for their family caregivers) has been developed based on the objectives of the current study and with reference to

a recent publication on similar topics.[1-3] Additional scales were integrated to design this comprehensive survey study. The authors ascertained face validity based on literature and research experience in the area. The Chinese questionnaires have been viewed by a panel of six Hong Kong local experts, including one geriatric doctor, one clinical psychologist, two nurses, and two social workers. The first elderly questionnaire has been pilot tested on one site with a sample of 12 participants to test for feasibility. We then revised the survey in preparation for the main study. After the pilot test, the experts were invited to judge the content validity of the questions for the second time as the questionnaires were developed. The content validity index was calculated as excellent (CVI/AVR = 0.87 for elderly survey and 0.98 for caregiver survey).

Phase 1 Measurement

The AMT and FRAIL screening tools will be applied to select our participants. The interview for the frail elderly participants will be conducted if they are deemed eligible. The questionnaire contains seven parts: (A) Demographics and functioning (personal profile); (B) Healthcare experiences and attitude; (C) Expectations of EoLC, (D) Advanced Care Planning experience and attitude; (E) Advance Directives awareness, experience, and attitude (F) Ideal terminal/death environment (preferences on places of care and eventual death); and (G) Quality of Life.

(A) Demographic information including age, sex, educational level, marital status, religion, financial source, type of nursing home, family members, self-reported health and pain severity, and bereavement experience, etc., will be collected. To assess daily functioning, frailty, depressive symptoms, and suicidal ideation, we will use the following respective scales, 10-item Barthel Index on ADL,[17] 5-item FRAIL,[15] Geriatric Depression Scale GDS-4, and a single-item suicidal ideation assessment.[18]

(B) The participants will be asked to share their experience of and attitude toward life-sustaining treatment and previous hospitalisation according to questions we have devised.

(C) The participants will be asked to rate their opinions on decision making with regard to LST in a hypothetical dying scenario, and their attitudes on quality of life at the end of life. The hypothetical dying scenario will be described in one phrase as "becoming seriously ill but with no cure available" for themselves.

(D) The participants will be asked about their awareness and experience or participation in ACP, their attitudes and preferred communication with others, as well as their reasons for rejecting the idea of ACP.

(E) Participants will be asked about their awareness of a living will and AD, and about their current consideration in formulating their written preferences on medical decisions and AD. The reasons behind their choices and the persons who introduced these topics to them will also be explored.

(F) The participants will be asked to rate their opinions on their hypothetical dying situation, i.e., the ideal places of their terminal care and death. They will be asked about their preferences regarding dying alone or having certain persons around them during their own eventual death.

(G) The McGill Quality of Life (M-QoL-HK) questionnaire will be used to measure Quality of Life among Hong Kong adults. Through a ten-point Likert Scale of 17 items, M-QoL measures four dimensions, including physical health, psychological/mental health, spiritual wellbeing, and overall quality of life. The items in M-QoL are considered applicable to both elderly people, palliative care patients, and caregivers by authors in the validated context of Hong Kong.[19]

Phase 2 Measurement

The questionnaire for family caregivers contains eight parts: (A) Their relationship with the elderly person; (B) Healthcare experiences and attitudes, and preferences for EoLC; (C) Expectations of EoLC, (D) Advanced Care Planning experiences and attitudes; (E) awareness, experience, and attitudes toward Advance Directives (F) Ideal terminal/dying situations (preferences with respect to places of care and eventual death); (G) Quality of Life; and (H) Supplementary information on demographics, financial support for caregiving, bereavement experience, and self-rated health (personal profile). The contents are similar to the elderly survey version with slight changes in wording to include an item that measures the caregivers' understanding of the elderly person's own perspective. Most of the questions are closed-ended, while there are open-ended questions for the caregivers to express their own opinions.

For both versions of surveys, there is a small ending section where interview staff can write their observation notes on respondents' emotions. Interviewers may also mark any words such as 'euthanasia' or 'hastened death' if these are mentioned during the conversations.[20]

Completion time for the interview is estimated to be 30-45 minutes. The RA will read out and explain all survey items one by one to the respondents to ensure the quality of the data collection. Furthermore, the respondents are not allowed to change their answer once the questions have been answered.

Patient and Public Involvement (PPI) statement

Potential barriers to study this population with PPI include the challenges of engaging the local elderly home management given that service providers are motivated to protect their residents and may hesitate before to aid research, especially without formal ethical approval. The survey was developed after consultation with public representatives, such as experienced staff members who work with the target population. We did not directly involve elderly people at the initial stage of this study as we did not have any pre-established partnership with local RCHEs. The revision of the survey content based on pilot responses took the elderly participants' feedback into account. We radically revised the survey content by deleting some awareness items, changing the wording to make the current survey easier to use in a formal study. Furthermore, we plan to disseminate the study findings in plain language in elderly homes and to the general public in the future, and their responses to the findings can influence the development of EoLC policy and practice in Hong Kong further.

Data Analysis

IBM SPSS and Mplus will be used for the statistical analyses. Descriptive analysis will first be conducted on demographics. Response frequencies for each measure will be tabulated, and the corresponding proportions will be calculated by dividing the frequency by the number of respondents. We plan to apply Logistic Regression Analysis to investigate independent predictors of our outcomes of interests, for example, the participants' preference to have communication on ACP for their own terminal care. The associations of sociodemographic characteristics, frailty, depression, and functioning status with the outcomes will be analysed.

We will apply Kappa Statistics to examine paired results between the frail elderly persons and their family caregivers. Preferences for life-sustaining treatment will be expressed in 3x2 tables and described in terms of percentage agreement and the kappa coefficient. The level of agreement will be described using indices such as 'agreement index' developed in the literature on treatment preferences. Where a caregiver could accurately interpret an elderly participant's preference in LST, whether that was for active treatment, against LST, or uncertain, they will gain a score of one. Thus, we will use a total score of 0 (no ability) through 8 (full ability) to know or estimate the family members' preferences in treatment for elderly residents who were at terminal stages from survey hypothetical scenarios. Combined agreement scores from all matched pairs of family caregivers and elderly respondents will represent overall agreement in the survey sample. Finally, we plan to calculate the association between elderly participants and family caregivers' characteristics and agreement scores through multiple linear regression.

ETHICS AND DISSEMINATION

The cross-sectional survey has been approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (IRB Reference number: UW 18-443). To respect the principles of human dignity and voluntary participation in the study, a comprehensive verbal explanation and a comprehensive information sheet will be provided to the participants (family caregivers and the frail elderly home residents) during the recruitment period, prior to the commencement of data collection. The purpose and procedure of the study, as well as the risks and benefits of participation, will be explained. Respondents will be encouraged to clarify any queries related to the study with the research staff. Oral consent will be obtained from elderly participants before commencing the individual interviews. For their family

members, respondents can opt for either oral or written consent. Participation will be entirely voluntary, and respondents will be informed of their rights to withdraw or refuse to give information at any time without incurring penalties or deprivation of services.

There is a chance that these interviews may cause some stress for elderly participants beyond what is typical in their casual daily conversations given that as the survey covers death-related content. In the pilot interviews, signs of stress occasionally appeared as expected. Participants were asked whether they wanted to continue or not, and then their wishes were respected. Similarly, in the future interviews during the proposed study, the survey process will be paused in cases when participants are willing to continue despite stress to reduce potential harm to participants. The researchers will closely observe the reactions of the elderly participants. Additionally, relaxation techniques will be taught to the elderly participants on-site as needed. This will be documented in our survey and referred to staff for appropriate follow-up. Moreover, positive answers to the item on suicidal ideation item and those with depression symptoms at the cut-off score of 2 or above will be brought to the attention of the elderly home manager.[18]

The survey project officially began on November 1, 2018, and we aim to complete the project by October 30, 2021. Our results of the proposed cross-sectional study will be reported with reference to the international statement in the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist for cross-sectional studies.[21] The findings will be disseminated through international conference presentations and peer-reviewed academic journal publications. Meanwhile, a report in plain language will be shared with our partner elderly homes. The evidence gathered from this study has the potential to benefit research on EoLC both locally and internationally, and to further inform practitioners on the

desires and the EoLC needs of the frail elderly people and their caregivers. It is very important to share the knowledge that we gain on the preferences of frail elderly home residents with professionals in healthcare sectors, such as physicians, direct service staff, and the larger community. Understanding their wishes can be a great step towards developing better quality EoLC for the 8% of Hong Kong elderly population who reside in RCHEs.[22]

AUTHOR CONTRIBUTIONS

CL, PC, and BY conceptualized the survey design. BY and PC drafted the manuscript protocol. BY prepared the IRB application and the amendment from collaborative input. BY and XX conducted pilot survey interviews. BY and XX made the revision with CL. All the authors, including BY, XX, PC, NT, DC, FC, and CL, contributed to the development of the survey protocol and approved the final version of the manuscript.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

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Preferences for End-of-Life Care: A Study Protocol for a Cross-sectional Survey of Chinese Frail Elderly Home Residents in Hong Kong

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ABSTRACT

Introduction: Existing literature on attitudes toward end-of-life care (EoLC) covers the general public but has little information on the frail elderly population. The aim of the current study is to investigate the preferences of Chinese frail elderly home residents with respect to EoLC by conducting cross-sectional surveys.

Methods and analysis: Surveys, including resident and family versions, were developed based on the existing literature and our pilot interviews. The targeted participants were 400 frail elderly home residents (aged ≥65 years old) and 200 family caregivers. Purposive sampling will be used as each elderly home will help to recruit 5 to 15 elderly participants for the study. Descriptive analysis and modelling will be used to examine preferences on EoLC and related factors, as well as to compare the responses of elderly home residents with those of their family caregivers.

Ethics and dissemination: The cross-sectional survey has obtained IRB approval. Confidentiality and safety issues will be carefully observed. The results of the study will be disseminated through international conferences, peer-reviewed academic journal publications, and a report in plain language to be shared with elderly residential homes.

Strengths and limitations of this study:

- Survey versions were developed to inquire into the preference of both the frail elderly home residents and family caregivers.
- For the first time, surveys on elderly people's attitudes towards EoLC cover all main areas of Hong Kong.
- The cross-sectional design of this study cannot conclude causality.
- Participants with communication problems (i.e., deafness or aphasia) were excluded due

to the nature of the data collection method.

INTRODUCTION

End-of-life care (EoLC) attitudes have increasingly attracted attention in peer-reviewed journals.[1-4] The literature indicates that EoLC for terminally ill patients can include many challenges, for example, access to services, quality of care, awareness, attitudes, communication, and decision making.[4] Advance care planning (ACP) and advance directives (ADs) have been promoted in order to discover patient attitudes towards their EoLC,[5] with the benevolent intention that these processes help to honour their wishes or preferences for a good death. An AD is one of the potential outcomes of participation in ACP. Both ADs and ACP involve the patients' understanding of life-sustaining treatment (LST).[6] Several studies have demonstrated that the awareness of AD is low in Chinese populations.[1-3, 5] Moreover, a recent systematic review summarised 107 EoLC studies in Hong Kong in the past decade reported a primary focus on AD rather than ACP.[4] Studies of Chinese family attitudes towards ACP present mixed findings according to Lee's review in 2014.[5] Therefore, our study aims to investigate the preferences of Chinese frail elderly home residents with respect to EoLC. We explore their preferences along with relevant factors, such as ACP and AD awareness, preferences concerning LST, decision-making, and preferred place of death, by conducting original surveys with frail elderly home residents and their family caregivers.

By definition, frailty refers to a vulnerable state in which there is an increased risk of hospitalisation, deterioration in functioning, and mortality.[7] Frail elderly people are particularly understudied, and thus their voices have rarely been heard by academics, politicians, or the wider public. Though we found the most recent report on the prevalence of Hong Kong

general public preferences regarding EoLC and preferred place of death,[1, 8] these results were generated from telephone landline surveys. The public participants who joined the brief phone interview may not represent the views of frail elderly home residents on these sensitive topics. The landline phone calls could not reach the frail elderly population living in residential care homes for the elderly (RCHEs), including nursing homes, care and attention homes, and other types of homes that provide comprehensive care for dependent people.[9] Our study will help to bridge this knowledge gap. Face-to-face interviews with frail elderly home residents will help to gain a better understanding of their attitudes.

The present study is significant as the population of Hong Kong ranks top in life expectancy around the globe, and the percentage of its ageing population is rising.[1, 9] The government officially projects that the percentage of elderly residents aged 65 and above will continue to grow from over one million to 2.61 million in 2058 (36% of the Hong Kong population).[1, 10] This is much higher than estimates of the global elderly population (21.1% in 2050).[11] At present, the demands for residential elderly care services in Hong Kong remain overwhelming, with average waiting time as long as 24 months for admission.[12] Due to priority considerations, frailty is one of the primary characteristics taken into account for elderly people being admitted to Hong Kong RCHEs.[9] Therefore, it is critically important to study the elderly home residents with pre-frail or frail statuses as they are most likely to receive EoLC in residential homes.[9]

Meanwhile, knowledge about the region must be urgently updated as the only studies on EoLC among elderly home residents in Hong Kong were conducted roughly ten years ago.[4, 6, 12] Hypothesising those factors that influence their preferences from the existing literature enables us to explore additional possible predictors. The present study will use a comprehensive

design to explore the under-researched topic of EoLC preferences of an understudied population: frail elderly home residents. Within families, caregivers' attitudes are also crucial, as they play a significant role as surrogate decision-makers in the future circumstance of an elderly family member, who does not have an AD or ACP, losing the capacity to make decisions on their own. Families often find making EoLC decisions very stressful.[13, 14] The systematic review by Wang and Chan shows that family caregivers in Hong Kong have also been an insufficiently studied population.[4] Thus, it is worth further investigation of caregiver's attitudes, and so we include this comparative perspective in our analysis. This is consistent with the World Health Organization's initiative to build an age-friendly environment.[11] To enhance the quality of EoLC in RCHEs, our survey findings will be a helpful reference to further identifying some directions for public education and other interventions in order to meet the needs of Hong Kong's frail elderly home residents.

Research questions

Phase 1: Survey of elderly home residents

What is the level of awareness of such terms as living will, AD, or ACP in Hong Kong among the frail elderly people, and what are their preferences with regard to ACP, decision-making, LST, AD, EoLC, and preferred place of death?

Phase 2: Family caregiver survey

What is the level of awareness of such terms such as living will, AD, or ACP in Hong Kong among family caregivers, and what are their attitudes of elderly family members' preferences?

METHODS AND ANALYSIS

Design

Prior to the main cross-sectional study, a pilot questionnaire has been completed on one site with a sample of 12 participants in an RCHE. The feasibility of the survey content was assessed. During our pilot survey interviews, we found the majority (10 out of 12) of participants who agreed to join the study were happy or felt it was acceptable to discuss EoLC issues with us, while the remaining two participants lost interest or refused to continue in the middle of the interviews, and their withdrawal was respected. Afterwards, no severe distress was reported or observed. Similarly, the existing literature shows that elderly people in Hong Kong facilities are willing to talk about issues related to death and dying.[12] This offers our survey the advantage of gaining first-hand knowledge about the elderly people's preferences and experiences. In the pilot, only one participant out of the 12 participants had heard of AD or ACP before our interviews. This low level of awareness is consistent with earlier surveys that reported that 96% and 85.7% of people surveyed had never heard of AD.[1,8]

We conducted four phone interviews with family caregivers as a pilot for the family version of the survey. Three of the four interviews were completed, and the only dropout occurred part way through an interview when the participant incorrectly thought that our interview was an attempt to sell her something. Feasibility and acceptance of our survey appear high among frail elderly home residents and family caregivers in Hong Kong. We have made

modifications to the version for the elderly person to shorten the questionnaire to reduce the burden of participation. We have added explanations of ACP and AD in plain language so that it is easier for lay participants to understand. We have provided more choices on why participants do or do not want to consider initiating ACP or an AD based on the pilot findings.

Outcomes

i) Phase 1 Primary outcome: Preferences of the frail elderly person on ACP.

ii) Phase 1 Secondary outcomes: The frail elderly person's level of awareness and preferences with regard to LST, decision-making, AD, preferred place of death, and quality of life.

iii) Phase 2 Primary outcome: Level of agreement between Family caregivers' preferences and those of elderly's on ACP for elderly home residents.

iv) Phase 2 Secondary outcomes: Family caregivers' awareness of these terms and preferences with regard to LST, decision-making, ACP, AD, and preferred place of death.

Participants

Phase 1 Frail elderly home residents

The inclusion criteria for the frail elderly participants are as follows:

i) At least 65 years of age;

ii) Chinese in elderly homes who can speak and understand either Cantonese or Mandarin;

iii) Either pre-frail or frail status (rating 1-5 on FRAIL).[15]

The exclusion criteria for frail elderly participants are:

i) Cognitive impairment (scoring five or below on the abbreviated mental test [AMT]).[16] To screen for ineligibility due to cognitive impairment, the Chinese AMT will be used.

ii) Communication problems due to functional impairment (for example, deafness or aphasia).

Phase 2 Family caregivers

The inclusion criteria for family caregiver participants are as follows

i) Hong Kong Chinese adults (18 years of age or above) who can speak and understand Cantonese or Mandarin.

The exclusion criteria for family caregiver participants are:

(i) Communication problems due to functional (deafness or aphasia) or intellectual impairment.

Recruitment

We plan to partner with 32 local elderly homes with an average of 12 residents from each home. Under the most conservative scenario (assuming the true proportion is 50%), a sample of 384 elderly residents will be required to give a 95% confidence interval for the proportion of people who would prefer to have communication on ACP with a margin of error of 5%. To cater for inter-correlation within residents in the same home, we assume ICC to be 0.05. We will expect to interview 400 elderly participants in order to collect their responses to the survey in the first phase. Assuming that around half of these elderly people will have family caregivers willing to join the study, 200 family caregivers will be interviewed in the second phase.

Using a purposive sampling method, we plan to select elderly homes in all main regions of Hong Kong (Hong Kong Island, Kowloon, and the New Territories) by sending out invitations via mail and by convenient professional networks. The managers of the elderly care homes will be approached via phone calls and asked permission to let us interview their elderly residents. The elderly residents in the homes will be invited in-person to participate in face-to-face survey interviews. The family caregivers can choose to join caregiver interviews via either face-to-face or via phone survey with our research staff at a time convenient as mutually agreed.

The facility staff will introduce us to the elderly candidates. There will be no monetary incentives offered to either the participants or the agencies involved. During the recruitment process, the research assistant (RA) will explain the study to the potential participants either in a private room (bedside/chairside) or in the corner of a common room to protect privacy. After seeking oral consent from residents to participate, the RA will administer the AMT and the five-item Frailty scale to screen out ineligible ones based on our exclusion criteria. The RA will then conduct an individual face-to-face interview with the participant using our designed questionnaire. Trained RAs will collect data during the interviews on either paper or digital form, depending on Internet availability. Digital devices (i.e., smartphones or tablets) for accessing the digital survey will be operated by the research staff during the interviews with the participants, and paper-based surveys will serve as a backup option.

Survey interviews

A structured questionnaire (one version for the frail elderly and the other version for their family caregivers) has been developed based on the objectives of the current study and with reference to

a recent publication on similar topics.[1-3] Additional valid scales from existing evidence were integrated to measure important factors (for example, geriatric depressive symptoms[17]) that could potentially affect participants' EoLC attitude in this comprehensive survey study. The authors ascertained face validity based on literature and research experience in the area. The Chinese questionnaires have been viewed by a panel of six Hong Kong local experts, including one geriatric doctor, one clinical psychologist, two nurses, and two social workers. The first elderly questionnaire has been pilot tested on one site with a sample of 12 participants to test for feasibility. We then revised the survey in preparation for the main study. After the pilot test, the experts were invited to judge the content validity of the questions for the second time as the questionnaires were developed. The content validity index was calculated as excellent (CVI/AVR = 0.87 for elderly survey and 0.98 for caregiver survey).

Phase 1 Measurement

The AMT and FRAIL screening tools will be applied to select our participants. The interview for the frail elderly participants will be conducted if they are deemed eligible. The questionnaire contains seven parts: (A) Demographics and functioning (personal profile); (B) Healthcare experiences and attitude; (C) Expectations of EoLC, (D) Advanced Care Planning experience and attitude; (E) Advance Directives awareness, experience, and attitude (F) Ideal terminal/death environment (preferences on places of care and eventual death); and (G) Quality of Life.

(A) Demographic information including age, sex, educational level, marital status, religion, financial source, type of nursing home, family members, self-reported health and pain severity, and bereavement experience, etc., will be collected. To assess daily functioning, frailty, depressive symptoms, and suicidal ideation, we will use the following respective scales, 10-item

Barthel Index on ADL,[18] 5-item FRAIL,[15] Geriatric Depression Scale GDS-4, and a single-item suicidal ideation assessment.[19]

(B) The participants will be asked to share their experience of and attitude toward life-sustaining treatment and previous hospitalisation according to questions we have devised.

(C) The participants will be asked to rate their opinions on decision making with regard to LST in a hypothetical dying scenario, and their attitudes on quality of life at the end of life. The hypothetical dying scenario will be described in one phrase as "becoming seriously ill but with no cure available" for themselves.

(D) The participants will be asked about their awareness and experience or participation in ACP, their attitudes and preferred communication with others, as well as their reasons for rejecting the idea of ACP.

(E) Participants will be asked about their awareness of a living will and AD, and about their current consideration in formulating their written preferences on medical decisions and AD. The reasons behind their choices and the persons who introduced these topics to them will also be explored.

(F) The participants will be asked to rate their opinions on their hypothetical dying situation, i.e., the ideal places of their terminal care and death. They will be asked about their preferences regarding dying alone or having certain persons around them during their own eventual death.

(G) The McGill Quality of Life (M-QoL-HK) questionnaire will be used to measure Quality of Life among Hong Kong adults. Through a ten-point Likert Scale of 17 items, M-QoL measures four dimensions, including physical health, psychological/mental health, spiritual wellbeing, and overall quality of life. The items in M-QoL are considered applicable to both

elderly people, palliative care patients, and caregivers by authors in the validated context of Hong Kong.[20]

Phase 2 Measurement

The questionnaire for family caregivers contains eight parts: (A) Their relationship with the elderly person; (B) Healthcare experiences and attitudes, and preferences for EoLC; (C) Expectations of EoLC, (D) Advanced Care Planning experiences and attitudes; (E) awareness, experience, and attitudes toward Advance Directives (F) Ideal terminal/dying situations (preferences with respect to places of care and eventual death); (G) Quality of Life; and (H) Supplementary information on demographics, financial support for caregiving, bereavement experience, and self-rated health (personal profile). The contents are similar to the elderly survey version with slight changes in wording to include an item that measures the caregivers' understanding of the elderly person's own perspective. Most of the questions are closed-ended, while there are open-ended questions for the caregivers to express their own opinions.

For both versions of surveys, there is a small ending section where interview staff can write their observation notes on respondents' emotions. Interviewers may also mark any words such as 'euthanasia' or 'hastened death' if these are mentioned during the conversations.[21]

Completion time for the interview is estimated to be 30-45 minutes. The RA will read out and explain all survey items one by one to the respondents to ensure the quality of the data collection. Furthermore, the respondents are not allowed to change their answer once the questions have been answered.

Patient and Public Involvement (PPI) statement

Potential barriers to study this population with PPI include the challenges of engaging the local elderly home management given that service providers are motivated to protect their residents and may hesitate before to aid research, especially without formal ethical approval. The survey was developed after consultation with public representatives, such as experienced staff members who work with the target population. We did not directly involve elderly people at the initial stage of this study as we did not have any pre-established partnership with local RCHEs. The revision of the survey content based on pilot responses took the elderly participants' feedback into account. We radically revised the survey content by deleting some awareness items, changing the wording to make the current survey easier to use in a formal study. Furthermore, we plan to disseminate the study findings in plain language in elderly homes and to the general public in the future, and their responses to the findings can influence the development of EoLC policy and practice in Hong Kong further.

Data Analysis

IBM SPSS and Mplus will be used for the statistical analyses. Descriptive analysis will first be conducted on demographics. Response frequencies for each measure will be tabulated, and the corresponding proportions will be calculated by dividing the frequency by the number of respondents. We plan to apply Logistic Regression Analysis to investigate independent predictors of our outcomes of interests, for example, the participants' preference to have communication on ACP for their own terminal care. The associations of sociodemographic characteristics, frailty, depression, and functioning status with the outcomes will be analysed.

We will apply Kappa Statistics to examine paired results between the frail elderly persons and their family caregivers. Preferences for life-sustaining treatment will be expressed in 3x2 tables and described in terms of percentage agreement and the kappa coefficient. The level of agreement will be described using indices such as 'agreement index' developed in the literature on treatment preferences. Where a caregiver could accurately interpret an elderly participant's preference in LST, whether that was for active treatment, against LST, or uncertain, they will gain a score of one. Thus, we will use a total score of 0 (no ability) through 8 (full ability) to know or estimate the family members' preferences in treatment for elderly residents who were at terminal stages from survey hypothetical scenarios. Combined agreement scores from all matched pairs of family caregivers and elderly respondents will represent overall agreement in the survey sample. Finally, we plan to calculate the association between elderly participants and family caregivers' characteristics and agreement scores through multiple linear regression.

ETHICS AND DISSEMINATION

The cross-sectional survey has been approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (IRB Reference number: UW 18-443). To respect the principles of human dignity and voluntary participation in the study, a comprehensive verbal explanation and a comprehensive information sheet will be provided to the participants (family caregivers and the frail elderly home residents) during the recruitment period, prior to the commencement of data collection. The purpose and procedure of the study, as well as the risks and benefits of participation, will be explained. Respondents will be encouraged to clarify any queries related to the study with the research staff. Oral consent will be obtained from elderly participants before commencing the individual interviews. For their family

members, respondents can opt for either oral or written consent. Participation will be entirely voluntary, and respondents will be informed of their rights to withdraw or refuse to give information at any time without incurring penalties or deprivation of services.

There is a chance that these interviews may cause some stress for elderly participants beyond what is typical in their casual daily conversations given that as the survey covers death-related content. In the pilot interviews, signs of stress occasionally appeared as expected. Participants were asked whether they wanted to continue or not, and then their wishes were respected. Similarly, in the future interviews during the proposed study, the survey process will be paused in cases when participants are willing to continue despite stress to reduce potential harm to participants. The researchers will closely observe the reactions of the elderly participants. Additionally, relaxation techniques will be taught to the elderly participants on-site as needed. This will be documented in our survey and referred to staff for appropriate follow-up. Moreover, positive answers to the item on suicidal ideation item and those with depression symptoms at the cut-off score of 2 or above will be brought to the attention of the elderly home manager.[19]

The survey project officially began on November 1, 2018, and we aim to complete the project by October 30, 2021. Our results of the proposed cross-sectional study will be reported with reference to the international statement in the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist for cross-sectional studies.[22] The findings will be disseminated through international conference presentations and peer-reviewed academic journal publications. Meanwhile, a report in plain language will be shared with our partner elderly homes. The evidence gathered from this study has the potential to benefit research on EoLC both locally and internationally, and to further inform practitioners on the

desires and the EoLC needs of the frail elderly people and their caregivers. It is very important to share the knowledge that we gain on the preferences of frail elderly home residents with professionals in healthcare sectors, such as physicians, direct service staff, and the larger community. Understanding their wishes can be a great step towards developing better quality EoLC for the 8% of Hong Kong elderly population who reside in RCHEs.[23]

AUTHOR CONTRIBUTIONS

CL, PC, and BY conceptualized the survey design. BY and PC drafted the manuscript protocol. BY prepared the IRB application and the amendment from collaborative input. BY and XX conducted pilot survey interviews. BY and XX made the revision with CL. All the authors, including BY, XX, PC, NT, DC, FC, and CL, contributed to the development of the survey protocol and approved the final version of the manuscript.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

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