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Submitting author: Prof Christine M.S. FANG

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The Older Adultsâ€™ Voice on Realizing Hopes for Dying Well

Fang MSC (1), Kong ST (1), Lou VWQ (1)

(1) Sau Po Centre on Aging, Faculty of Social Sciences, University of Hong Kong

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Introduction

Older adults should have the final word on their last journey, but care professionals and family members are left to make these difficult choices. The perspectives of older adults in relation to their emotions, preparations and concerns over the process of dying should inform future service enhancement to achieve dignified dying for an aging population.

Objectives

To solicit and make meaning of the emotions and barriers to realizing the hopes for dying well in Hong Kong, as articulated by middle aged and older adults themselves

Methodology

1. Participatory questionnaire design: 4 focus groups, involving 18 older adults, were carried out to understand their thought and decision process in preparing for death.
2. Online survey: Hosted in an online survey platform. Respondents recruited through social media, academic and NGO networks, and community groups with a focus on end-of-life issues.
3. Collaborative interpretation of findings: 2 focus groups with older adults and their carers were organized to make sense of the findings of the online survey.
4. Analysis: Thematic analysis of qualitative data collected from focus groups pre and post online survey. Descriptive analysis is carried out on 136 questionnaires completed by respondents aged 56 or above, based on a sample of 458 respondents in total.

Result

1) Relational taboo rather than social taboo is the barrier. Respondents aged 56 or above generally accept â€œdeath as part of the life courseâ€™ (79.4%). While

“relational taboo” appears to be more prominent than “social taboo” as “missing their loved ones” (39%) and “worries over the wellbeing of the family” (11.8%) were more frequently chosen emotions than “fear of misfortune” (1%).

2) An apparent gap between talking about death and taking actions to prepare for death. A sizable proportion of middle aged and old aged respondents had thought about their preferences in respect to psychological, medical, relational, financial, spiritual and post-mortem preparations for death (range = 37.5 – 50.7%). However, way less respondents of these age groups had talked about their preferences with their families (17.6-34.6%), and even less materialized them by writing them down or acting on them (4.4-26.5%).

3) Accepting the reality that there is no real choice in place of death and place of care, older adults articulated their sense of lack of choice over dying options in the focus groups, and the online survey then allowed respondents to rank the desired care environment and process of care at the end of life.

Conclusion: Voices among older adults have shed light on the need for developing strategies to break the “relational taboo” facing dying patients when death is imminent, and that for improving care tenor to achieved perceived “good death”.