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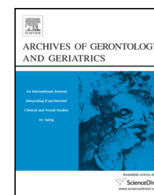

Original article

Content of advance care planning among Japanese elderly people living at home: A qualitative study

Yoshihisa Hirakawa*, Chifa Chiang, Esayas Haregot Hilawe, Atsuko Aoyama

Department of Public Health and Health Systems, Nagoya University Graduate School of Medicine, Japan

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ABSTRACT

Purpose of study: Elderly peoples' values and preferences for end-of-life care have not yet known in details. The aim of the present study was to investigate the end-of-life wishes and decision making among Japanese elderly people who required home care services. The study was designed to qualitative research strategies, using face to face interview data recorded in nursing care records, with a focus on advance care planning.

Design and methods: A total of 102 elderly people (47 males, 55 females) of 6 home care support offices in Hyogo prefecture participated.

Results and implications: We finally extracted the following 5 themes: *anxiety about the future, abandonment of control, clinging to current daily life, precarious mutual support, delegating decision-making.* While elderly people living at home generally feel anxious and fearful about the future, they seemed to try to avoid thinking too seriously about possible complications in their life.

They also tend to leave end-of-life decision to someone else, and their decisions tend to change as they advance in age and as their condition deteriorates. Our findings suggest that medical professionals and care managers always support their patients' decisions, allowing for the views of the informal caregivers on whom elderly people rely for decision-making.

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1. Introduction

Advance care planning (ACP) is a process that enables individuals to convey their preferences and make plans about their future health care and end-of-life care options to family caregivers and health care professionals (Detering, Hancock, Reade, & Silvester, 2010; Ke, Huang, O'Connor, & Lee, 2015; Oczkowski, Chung, Hanvey, Lawrence, & John, 2016; Takeshita, Ikeda, Sone, & Moriyama, 2015). Numerous studies and literature suggest that ACP improves the expression of individuals' preferences for end-of-life care and that it should thus be regarded as the gold standard in the care of patients with life-limiting illnesses (Detering et al., 2010; Ke et al., 2015; Martin, Hayes, Gregorevic, & Lim, 2016; Oczkowski et al., 2016; Sharp, Moran, Kuhn, & Barclay, 2013; Takeshita et al., 2015; Watanabe et al., 2013). ACP is also of particular importance for elderly people living in the community who require nursing care because many of them will eventually decline progressively to a state in which they can no longer communicate their end-of-life care preferences.

However, there are several barriers to adapting ACP to the Japanese long-term care system. First, ACP is still not a legal process in Japan and it has therefore not yet been widely spread nationwide (Takeshita et al., 2015). Second, the ACP interview guides that have been developed and published in other countries may not be suitable for the Japanese people due to cultural differences and must be modified (Clayton et al., 2007). From a European and North American point of view, patient autonomy is highly valued, whereas in Japan, there is a unique concept of life and death, generally represented by a submissive attitude toward medical professionals on the part of patients or the acceptance of their own circumstances as fate (Hattori et al., 2005; Japan Geriatric Society, 2012). Finally, care managers play a vital role in assessing clients' needs, creating care plans and monitoring conditions from the early stage of frailty; they could potentially contribute to enhancing their clients' participation during ACP (Hirakawa, Kuzuya, Enoki, & Uemura, 2011; Martin et al., 2016). Care managers are a group of professionals introduced to draw up care plans and coordinate long-term care services for individual clients under Japan's long-term care insurance system. The certificate of care manager is given to the licensed medical or welfare professionals, *e.g.*, nurses, social workers, *etc,* and professional caregivers, who have passed an examination and

* Corresponding author.
E-mail address: y.hirakawa@med.nagoya-u.ac.jp (Y. Hirakawa).

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received a prescribed on-the-job training (Tsutui & Muramatsu, 2005).

Many Japanese care managers are non-medical professionals who are not properly trained to discuss death or end-of-life wishes with elderly people and their families (Martin et al., 2016).

Care managers could better frame the issues facing elderly people regarding end-of-life and formulate key questions to their clients, if they learn the general ACP trends for elderly people in the community. Indeed, if care managers are better equipped to ask important questions about sensitive topics such as end-of-life issues, communication with elderly people and their families is likely to improve (Clayton et al., 2007; Oczkowski et al., 2016).

Details of elderly peoples' values and preferences for end-of-life care in real-world settings (Triplett et al., 2008) are not fully investigated, since most previous studies focused only on the frequency of end-of-life care discussions, completion of advance care planning, and concordance between the care desired and the care received by patients (Detering et al., 2010; Oczkowski et al., 2016; Triplett et al., 2008). The aim of the present study was to investigate the end-of-life wishes and decision making among Japanese elderly people who required home care services.

2. Methods

The study was designed by qualitative research strategies, using face to face interview data recorded in nursing care records, with a focus on advance care planning.

2.1. Data collection

The study was conducted at 6 home care support offices of Himeji Medical Cooperative in Hyogo prefecture. The cooperative had been providing interview training to their care managers on daily basis. We recruited these particular participants because

Table 1
KJ method group organization: themes, subthemes and meaning units.

Theme	Sub-theme	Meaning unit
Anxiety about the future	Fear of loneliness	Loneliness is unavoidable as we grow older
		I can not ask my son for care support because I do not feel at ease with my daughter-in-law
	Dislike of hospitalization	I really dislike hospitals
		I want to remain at home as long as possible and avoid being hospitalized
	Fear of deterioration	I worry that I may not be able to discuss care services with the hospital or care service center if my condition deteriorates
		I will move to my daughter's house or go to the hospital in case my condition deteriorates
		I have heart disease and want to be hospitalized when my condition worsens
		I prefer to be hospitalized or insitituionalized at the end of my life because I am really worried about living alone
		If I develop severe dementia, I would like to be institutionalized to avoid becoming a burden on my wife
Abandonment of control		I do not know what I am going to do until I am in that situation
		I do not want to think about it for now
		I do not care about where I die
		I think I would have no choice but to be institutionalized in the future, just as my sister was
Delegating decision-making		I want to delegate my care to my family because they are looking after me very well
		Because I live alone and have financial difficulties, I want to leave a power of attorney to my children
		I have not thought about it, but I hope my brother will take care of me in the last days of my life
Precarious mutual support		I want to stay with my wife and care for her even though she has dementia
		I would like to keep caring for my wife and continue to enjoy a hobby
		I want to continue managing daily life and caring for my demented husband so as not to impose on my children
		I am now caring for my sister and I am worried about her future
		I have to stay healthy until my demented husband passes away
		I have to go on with daily life and continue caring for my wife despite my worries about her future
Clinging to current daily life	Surrounded by good, caring people	I am grateful that my children, daughter-in-law, and day service center staff kindly take turns caring for me
		I am satisfied with the current situation and appreciate my wife's efforts in preparing good meals for me
		I hope to spend the last days of my life at home,enjoying good relations with friends, neighbours and family
		I would be happy if my son and his family came back to live with me in the future
		I want to die surrounded by family members
	Attachment to house	I want to stay in the house where my husband and I built a life together despite the fact that he was rigid
		I want to stay in the house that I built until the very end of my life
	Maintaining average living standard	I want to keep an average standard of living
	Desire for freedom	I want to spend daily life at home and do as I please
		If my health deteriorates, I want to be admitted to an institution with a relaxed atmosphere
		I want to spend daily life taking naps whenever I feel like it
		I do not feel like meeting people who might bother me
	Desire for autonomy	I will continue to exercise in order to keep up with my current daily living activities
		Wherever I am, I hope to stay healthy until I pass away
		Due to leg pain, I am unable to continue farming despite my wishes
		I would like to cycle to the market and shop for my favorite things
		I really enjoy household chores such as laundry, shopping and cooking because I have done them since childhood
		I want to avoid falling down and end up bed-ridden
		I want to manage my life on my own until the end

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