

Advanced Care Planning: An Educational Intervention for the Elderly in Indonesia

A Pilot Randomized Controlled Trial

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Abstract: Discussions involving Advanced Care Planning (ACP) can be challenging in the setting of early dementia. In this study, we aimed to evaluate an educational intervention that focused on ACP in elderly people with mild cognitive impairment in Indonesia. This small pilot study used a randomized control trial design. A total of 19 respondents with mild cognitive disorders were recruited and randomly assigned to either an experimental (video, discussion, and print material) or control group (print material alone). Knowledge of ACP, confidence in making end-of-life decisions, and care preferences were compared between the two groups. A significant increase was noted in knowledge ($p = 0.002$) and confidence ($p = 0.003$), yet regarding preferences, only 30% of respondents in the experimental group completed the ACP documentation, and therefore limited conclusions could be made. Providing information in different formats to people with a mild cognitive impairment may increase their ability to participate in ACP. Further research is needed involving greater numbers of respondents.

1 BACKGROUND

Respecting the choices that elderly people make, regarding treatment preferences, is an important component of end-of-life care. Advanced Care Planning (ACP) is a mechanism by which health care professionals can broach sensitive discussions concerning death, dying, and document care preferences. ACP is a process that focuses on the individual and commonly involves healthcare professionals (doctors, nurses, psychologists, and social workers) and ideally family members (Robinson et al., 2012; Abel et al., 2013; Blackford & Street, 2013). The purpose of ACP is to document care preferences and appoint a surrogate decision maker if a person can no longer make decisions for themselves (Schaeffer, 2011).

An important element of ACP is clarifying a person's knowledge of their condition, treatments, beliefs, and identifying their wishes regarding care (Volandes et al., 2009; Deep et al., 2010). However, such discussions are often taboo in almost all countries in the Asia Pacific region (Con, 2008; National Hospice & Palliative Care Organization,

2009), including Indonesia. This hesitancy to discuss death and dying relates to cultural values and beliefs. For example, in the Philippines, many people believe that the future, including death, is in the hands of God and therefore making plans for the end-of-life care, including discussions regarding ACP, would be usurping God's authority and this is unacceptable (Con, 2008). In Indonesia, end-of-life discussions usually occur informally when reciting the Al- Qur'an. Consequently, in Indonesia, healthcare professionals, and carers alike, must discuss end-of-life issues with great sensitivity so they do not offend. Death is a universal phenomenon regardless of age, and, therefore, talking about death and dying is vital to the success of ACP (Silveira & Forman, 2012). While carrying out effective ACP for the elderly can be challenging, especially when in the presence of cultural taboos and cognitive decline, it is necessary for a "good" death to occur (Lim et al., 2012; Davies et al., 2014).

In Indonesia, the improvement in healthcare facilities and the growing economy has led to an increase in the standard of living and life expectancy amongst its citizens (Kementerian Kesehatan RI, 2014). These improved conditions have led to an

increase in the proportion of elderly people in the population. As a consequence, various chronic diseases of aging such as hypertension, osteoarthritis, and, importantly, cognitive impairment and dementia have increased (WHO, 2011). Cognitive impairment can make the elderly feel powerless when they are facing the end of life (WHO, 2011). One solution to minimizing this sense of powerlessness in the elderly is to introduce an Advance Care Planning information session into nursing homes (Vollandes et al., 2009; Deep et al., 2010).

Traditionally in Indonesia, healthcare professionals verbally deliver information about the end of life. This delivery method has limited success, especially when the person is elderly. This failure may be because the aging process can affect sight and hearing (Nugroho, 2008). In addition, the degree to which people understand verbal descriptions concerning complex medical conditions depends on their level of health (Vollandes et al., 2009). To overcome this problem, delivering information in several formats has been shown to improve health literacy. In a previous study in Australia, a video decision support tool for advanced dementia seemed to improve communication and decision making for patients by helping them to visualize future health states (Vollandes et al., 2009; Deep et al., 2010; Gjerberg et al., 2015). However, it is still unknown how the video qualitatively altered the client's cognition regarding their future care. This work will add information regarding cognition in the elderly after the use of the video decision support tool. People have different methods of learning. Some can receive information better visually, others through auditory means, or through a certain sense (Franzoni & Assar, 2009). These methods are affected by age, experience, physiology, culture, and many other factors. Powerful media and visualization techniques have shown to create lasting memories and improve recall (Bert P.M. Creemers & Creemers, 2007; Franzoni & Assar, 2009). There is no research to date that explores ACP discussions amongst the elderly with an early cognitive decline in Indonesia. Hence this study aims to address this gap.

2 METHODS

2.1 Study Design

The researcher used a pilot experimental research design with a randomized control group and a pre-

test/post-test design. The control group received standard care from the participating nursing home and a general information booklet on ACP. The experimental group received the modified ACP stages 1: introduction about end-of-life care and dementia; and 2: discussion about end-of-life preferences and progress of the disease.

2.2 Study Population, Sampling, and Procedure

The population in this study were elderly people who lived in a private nursing home in Surabaya, East Java, Indonesia. There were 19 respondents: nine in the control group and ten in the experimental group. The inclusion criteria were as follows: had a score of 17 or more on the Mini-Mental State Exam, indicating that they were cognitively able to consent to the study, were able to complete the first two stages of the ACP program, speak either Indonesian or Javanese, and have no major vision or hearing issues. The exclusion criteria were moderate to severe dementia, and/or other psychological disorders such as schizophrenia. Simple random sampling was the sampling technique used for this study. The collection of data occurred over a two-month period from May to June 2014. The ACP Phase 1 intervention was provided during two meetings per week for four weeks, and was delivered as a group presentation. The information for ACP Phase 2 was delivered in one meeting per week for two weeks. These latter meetings consisted of counseling and discussions and involved respondents, researchers, and nursing personnel.

2.3 Intervention

Modifications of the ACP information included additions made to the information booklet, a video, and a narrated PowerPoint presentation. The two videos used in this study were: 1) the video "Advanced Stage Dementia," taken from research conducted by Vollandes et al. (2009); the duration of the video is two minutes and 12 seconds; and 2) the video "ACP"; this video was taken from the Agency for Integrated Care (AIC), Taiwan, with a duration of six minutes and seven seconds.

2.4 Measures

The primary outcomes were knowledge and confidence. To measure these, questionnaires were used. The questionnaires, investigating knowledge and confidence, involved ten statements for which

the respondents had to answer true or false. The questionnaires that focused on confidence contained ten statements about the initiative of the elderly to follow the ACP program, persistence in completing the ACP program, and effort clients make in achieving the expected results. The secondary outcome included preferences regarding end-of-life care. The questionnaire that focused on preferences had only six items that allowed for open-ended responses and could be completed either by the researcher or the respondent. The questionnaire end of life six questions, including the following components: 1) the identity of the proxy; 2) valuable things for the elderly; 3) hopes and fears of the elderly; 4) medical care at the end of life; 5) the place at the end of life; and 6) place of burial and funeral. The instruments used in this study to measure the effectiveness of the intervention were developed by the researchers based on the literature review and previous research.

2.5 Data Analysis

Data analysis was conducted using the following statistical tests: 1) Mann Whitney (to determine the

different variables of knowledge and confidence, before and after treatment, between the two groups); 2) Wilcoxon (to test the variables of changes in knowledge and confidence before and after treatment in each group). Researchers determined by the degree of significance at $p < 0.05$. End-of-life care preferences were obtained through structured interviews and are described in the results section.

2.6 Ethical Clearance

This study was certified for ethical clearance by the Faculty of Public Health, Universitas Airlangga with the number 86/KEPK, April 7, 2014.

3 RESULTS

Respondents involved in this study were aged between 81 and 91 years of age. Their education level was mostly high school or equivalent, and this level of education was almost equal across the two groups (50% in the experimental group and 44.44 % in the control group). MMSE examination results showed that 67% of the control group and 60% of

Table 1: Cross tabulation of pre-test and post-test evidence of respondents' knowledge.

Knowledge	Control group				Experimental group			
	Pre-test		Post-test		Pre-test		Post-test	
	f	%	f	%	f	%	f	%
Good	0	0	1	11.11	0	0	10	100
Enough	7	77.77	6	66.66	10	100	0	0
Less	2	22.22	2	22.22	0	0	0	0
Total	9	100	9	100	10	100	10	100
Wilcoxon Signed Rank Test $p = 0.317$ ($p > 0.050$)					Wilcoxon Signed Rank Test $p = 0.002$ ($p < 0.050$)			

*f = frequency

Table 2: Cross tabulation of pre-test and post-test evidence of respondents' self-efficacy.

Confidence	Control group				Experimental group			
	Pre-test		Post-test		Pre-test		Post-test	
	f	%	f	%	f	%	f	%
High	1	11.11	1	11.11	0	0	9	90
Moderate	7	77.77	8	88.88	10	100	1	10
Low	1	11.11	0	0	0	0	0	0
Total	9	100	9	100	10	100	10	100
Wilcoxon Signed Rank Test $p = 0.317$ ($p > 0.050$)					Wilcoxon Signed Rank Test $p = 0.003$ ($p < 0.050$)			

*f = frequency

Table 3: The end-of-life care answer.

End-of-Life Care Planning			
1. The identity of the proxy	60% had already chosen the proxy	40% did not know	
	<i>“My first sons are people who are responsible for my medical treatment and give me money for this nursing home.”</i>	<i>“I have five children, and they will pay for my financial needs. If I have health problems they will hold a family meeting.”</i>	
2. Valuable things for the elderly	100% said the most valuable thing in their life is their family		
3. Hopes and fears of the elderly	80% of respondents said they still have unfulfilled expectations and fear	20% of respondents said they have no fear	
4. Medical care at the end of life	30% of respondents chose medical care that supports a quality of life without prolonging life	30% do not know about medical care	40% respondents chose medical care that prolonging life
5. The place for the end of life	50% of respondents chose end-of-life treatment at home with family	10% of respondents chose end-of-life treatment at the nursing home	40% of respondents chose end-of-life treatment in hospital
6. Place of burial and funeral.	70% respondents have still not made decisions for a place for burial and funeral	30% respondents have already chosen a place for burial and funeral	

the experimental group had mild cognitive impairment. There were only two types of religious affiliations that the respondents identified across the two groups; Islam (80% in the experimental group and 67% in the control group) and Christian (20% in the experimental group and 33% in the control group). Most respondents were married. All respondents were Indonesian with most from the island of Java. The reasons for the respondents entering the nursing home was largely due to their wishes (60 % in the experimental group and 45 % in the control group).

Based on Table 1, the good level of knowledge of the respondents in the experimental group was increased (n = 100%) compared to the control group (n = 11.11%). The statistical test in the experimental group showed there was a significant change of respondents' knowledge with a p-value = 0.002 (p<0.050).

Moreover, Table 2 also showed a high level of confidence in the respondents. In the experimental group there was an increase (n = 90% compared to the control group (n = 11.11%). The statistical test for the experimental group showed there was a significant change of respondents' confidence with a p-value = 0.003 (p<0.050).

None of the respondents in the control group could finish the question regarding end-of-life care

planning, while only 30% respondents in the experimental group completed the same question. The results of the discussion phase are explained in Table 3.

4 DISCUSSION

In summary, the results of this research suggest that changes in the method of giving information to the elderly can increase knowledge and the confidence to discuss treatment at the end of their lives. This condition does not allow the elderly to convey their desires regarding treatment at the end of life. Only 30% of the elderly can discuss their final treatment. Most respondents submit all decisions regarding late-life care to the family.

Based on the characteristics of the respondents, both treatment groups were Indonesian and mostly Javanese. The Javanese culture states that talking about death is taboo and precedes the will of God the Almighty, so talk of death is avoided by most elderly people. Also, history indicates that most elderly patients enter the home nursing by their own free will. This indicates that elderly people still have a very close relationship with their family; the selection of end-of-life care must be discussed with

the family. It is the cause of the elderly have not chosen by complete end of life care. Based on Indonesian culture, the elderly are important members of the extended family. Their family, especially their children, have a close relationship with them (Riasmini, Sahar, & Resnawati, 2013), so, every decision must be discussed with the family.

A third of the respondents who made the selection are no different to the seven other respondents regarding age, MMSE, or level of education. Improved knowledge, self-affection and behavior are also evident. This may be caused by their health being less favorable than other respondents. They already have limitations such as difficulty in walking, accompanied by post-stroke disorders. This is what allowed a third of respondents to make a choice for end-of-life care.

The Asian culture allows discussion about a person's chronic disease, but this is carried out by health personnel and takes place with family or people close to and not directly with the patient. Family support is strongly associated with selection decisions about end of life (Bravo et al., 2012; Lim et al., 2012; Goodman et al., 2013). Lim et al. (2012) also state that discussion regarding the end of life in the Asian culture is still considered taboo. Modified ACP stages 1 and 2 have helped respondents discuss end-of-life healthcare, but respondents are still not open to discussing it.

Stress affects perception response. In this study, stress perception relates to knowledge and confidence. Perceptual responses in this study are the end-of-life preferences. This study showed no difference in the theory. Improved knowledge and changes in confidence are not concomitant with the election of end-of-life care chosen by the elderly (Putra, 2011). Knowledge and confidence in the experimental group increased, but only a few respondents could discuss end-of-life care planning. This could be caused by the video provided not being based on condition of Indonesian culture. So, there are cultural factors that need to be considered in the formation of perceptual responses. The inability of the elderly to imagine the quality of their lives under certain circumstances, the so-called "paradoxical defect", and the benefits and disadvantages of the treatment received may be the reason that not all elderly people are capable of discussing and planning the end of their lives (Volandes et al., 2009; Deep et al., 2010).

This study has several limitations. ACP programs only used phase 1 and 2; phases 3–5 have not been carried out due to the time constraints of the study. Videos that were played by the

researchers were taken from Australia and Taiwan with dialogue in English and Mandarin, so respondents may have had difficulty understanding the contents of the video, although it was translated into Indonesian. Discussions during Phase 2 did not include the family. A small number of respondents were included because it was challenging to persuade respondents to join this research. In the future, a larger number should be included to achieve more reliable results. Researchers advice on further research includes involving the family in Phase 2 of the ACP and create videos regarding dementia and ACP based on Indonesian culture. This would facilitate all respondents making end-of-life care decisions. Nurses and nursing can motivate the elderly to make plans for their end-of-life care through the ACP modification program, as an independent nursing intervention.

5 CONCLUSIONS

An accurate and timely discussion of diseases and end-of-life care will help patients communicate with family and loved ones. ACP can give the elderly a real chance to have control over the ultimate choice of their lives. By educating the elderly on the topic of early treatment planning and effectively communicating and involving the families and medical personnel involved, nurses can provide patients with the best opportunity to make sure that others respect the final decision of their life.

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