Abstract of thesis entitled

“An Evidence-based Protocol of Advance Care Planning for Persons with Dementia in Memory Clinics”

Submitted by

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for the degree of Master of Nursing

at The University of Hong Kong

in July 2015

Dementia is a challenging health issue in the global explosive aging population. The increasing demand for early well planned medical choices for persons living with dementia (PWDs) by advance care planning (ACP) has not yet been satisfied in Hong Kong. An evidence-based protocol of ACP is warranted. This dissertation reports the existing evidence of effective ACP intervention and develops an ACP protocol with the use of video aided tool. This protocol can be implemented in a community setting such as a memory clinic. An evaluation plan of the proposed ACP protocol is also included.

Keywords: advance care planning, ACP, advance directive, AD, dementia, video-aiding tool
An Evidence-based Protocol of Advance Care Planning for

Persons with Dementia in Memory Clinics

by

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A thesis submitted in partial fulfillment of the requirement for

the degree of Master of Nursing

at The University of Hong Kong

July 2015
To My Beloved Parents in the Heaven

For

Love & Support in My Life
Declaration

I declare that this thesis represents my own work, except where due acknowledgement is made, and that it has not been previously included in a thesis, dissertation or report submitted to this University or to any other institution for a degree, diploma or other qualifications.

Signed

Wong Lai Fong
Acknowledgments

I would like to take this opportunity to express my sincere appreciation to my supervisor, Dr. Angela Leung from School of Nursing in The University of Hong Kong, for the enlightenment and guidance in accomplishing this dissertation.

I would like to extend my gratitude to my family for encouragement and support throughout my study of Master of Nursing.
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Chapter 1: Introduction

1.1 Background

1.1.1 Dementia

   Dementia is a syndrome caused by the progressive disease of the brain, disturbing various higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. It can be classified into three stages: early, middle and late stages. The periods of different stages vary and deterioration can go fast or slow. Each person is affected by dementia differently and not all the persons living with dementia (PWDs) have all the symptoms (Alzheimer’s disease International and World Health Organization, 2012).

1.1.2 Advance Directive & Advance Care Planning

   A person can state in a written document called an Advance Directive (AD) or a living will in advance about health care options, medical treatments and recovery choices when the person is unable to communicate or express one’s choices in the future (WHO, 2012). It is a legal document and effective only when the person is incapacitated and not able to express for oneself (NIA, 2012). The person can also state in the AD about the treatments and recovery choices that one does not want to receive, ensuring that person will not receive them against one’s wishes (WHO, 2012). The decisions for end-of-life (EOL) care may include cardiopulmonary resuscitation
(CPR), ventilator use, artificial nutrition (tube feeding) or artificial hydration (intravenous fluids) and comfort care (NIA, 2012).

Advance Care Planning (ACP) for healthcare, however, is a process of learning and considering for the options of decisions that persons have to be made in advance in an AD, of which allowing others to know their preferences and wishes (NIA, 2012). This is similar to the definition adopted by the Law Reform Commission (LRC), Food & Health Bureau (FHB) and Hospital Authority (HA) as follow: ACP is a communication process for the patients, healthcare providers, families and significant others about the kind of care being considered appropriately if the patients can no longer make decisions. Initiation of ACP usually happens when deterioration of patients’ conditions is anticipated in the future as they become incapable to make decisions or communicate about their wishes (FBH, 2009; HAHO, 2010; HKLRC, 2006; Teno et al., 1994). Numerous definitions of ACP exist in the literatures but the core meaning is more or less the same- ACP is the whole process to convey one’s wishes about the future care with written documentation being formulated.

1.1.3 Legal status of Advance Directives

The ACP will become meaningless if the ADs are not protected by the law or recognized guidelines. HA respected the importance of ADs by the internal HA Guidelines on Life-sustaining Treatment in the Terminally Ill only (HAHO, 2002).
HA waited until the release of the report of Substitute Decision-making and Advance Directives in Relation to Medical Treatment issued by the LRC in 2006 and the consultation paper of Introduction of the Concept of Advance Directives in Hong Kong issued by the FHB in 2009, HA then formulated the guidance for the clinicians on Advance Directives in Adults in 2010 (HAHO, 2010) and recently reviewed it (HAHO, 2014a).

Notwithstanding the release of LRC’s report and the FHB’s consultation paper, there are no legal statute and case law for the legal status of ADs in Hong Kong. However, the consultation paper points out that any person in Hong Kong is free to make ADs, of which having validity until there is challenge that the AD is made when the person is incapable or with undue influence (FHB, 2009).

Besides, the Code of Professional Conduct and the principle of self-determination require the physicians to respect patients’ wishes by means of ADs unless encountering unlawful acts such as euthanasia. Nevertheless, ADs are always being replaced by other statute when conflict with other legislation arises. In case of any dispute on the AD, the parties involved may need to apply to the court for a decision (FHB, 2009; HAHO, 2014b).
1.2 Affirming the Need and Significance

1.2.1 Prevalence of Dementia & Advance Directives

Hong Kong is facing the challenges from dementia inevitably. A study showed that overall weighted prevalence of dementia was about $6.1 \pm 0.7\%$ in Hong Kong (Chiu et al., 1998), while Lam’s study (2008) showed the overall prevalence of very mild dementia and mild dementia for persons aged 70 years or above were $8.5\%$ and $8.9\%$ respectively. Yu’s study (2012) projected for an increase of PWDs aged 60 and above from 103,433 in 2009 to 332,688 in 2039.

The overall prevalence of completed ADs, in contrast, is still low despite the effort in the advocacy by the regulatory bodies like the federal government agencies in the U.S. It is estimated for about $5\%$ to $15\%$ of the population having completed ADs in Kirschner’s study (2005). It should be highlighted that the community-dwelling older populations had a higher prevalence ($37\%$) of completed ADs in general (Ramsaroop et al., 2007). To my best knowledge that the local statistics for completed ADs are absent. The prevalence of completed ADs should be even lower in Hong Kong. The lower prevalence of ADs in Hong Kong can be attributable to the lack of publicity until recent official consultation in 2006, superficial understanding of situations requiring AD by the Hong Kong public (Pang et al., 2006) and poor knowledge of life-sustaining treatments for elderly in HK (Hui
et al., 1997).

1.2.2 End-of-Life Care & Advance Care Planning for the PWDs

Despite the increasing dementia prevalence, literatures show the EOL care is inadequate for PWDs. It is illustrated by Ahronheim’s study (2000) showing difficulty of the palliative care research team in influencing the care of PWDs with advanced stage of dementia. Also, Sampson’s study (2006) indicates the PWDs died in the acute setting had poor support for EOL care such as they were less likely to receive palliative medication.

Gjerdingen’s study (1999) shows the cognitively normal older adults did not desire the life-sustaining procedures regardless of dementia severity whereas Johnston’s study (1995) reveals the adult patients (mean age 50.9) want to discuss ADs in certain important domains such as early stage of the disease. These are in line with the component central to high quality EOL care- patient involvement in decisions for their care (Badrakalimuthu & Barclay, 2014). Meanwhile, close family members are incapable of predicting the elderly patients’ or PWDs’ preferences for care accurately (Bravo et al., 2012; Volandes et al., 2009a) and most types of dementia have the gradual and irreversible decline of cognitive functions. Thus, it is suggested that PWDs should make decisions in their early stages of disease regarding their medical treatments and other prospects (Alzheimer Europe, 2009). Literatures
also support for early initiation of ACP for the PWDs in the illness trajectory (Dening et al., 2011; Robinson, 2012; Volandes et al., 2009b), because it provides the opportunity for the PWDs to execute their self-determination by writing the ADs through the ACP, preserving and respecting their autonomy and human dignity (Alzheimer Europe, 2009). Moreover, HA revised the guidance for HA clinicians on Advance Directives in Adults (HAHO, 2014a) with the DNACPR (Do Not Attempt CPR) Guidelines (HAHO, 2014b) proclaimed, adding clinical condition of "other end-stage irreversible life-limiting condition" to AD with patients having “irreversible loss of major cerebral function and extremely poor functional status” as one of the examples. This act makes a path for ACP for PWDs.

Notwithstanding there are studies showing the change of CPR decisions with improved knowledge about the life-sustaining procedures, the wishes to be involved in decision-making for life-sustaining procedures by the elderly (Hui et al., 1997), the view of making EOL decisions positively by the PWDs with mild stage (Lee et al., 2006) and the effectiveness of an ACP program for frail nursing home residents (Chan & Pang, 2010), study for the measures facilitating the ACP earlier for the community-dwelling PWDs is still lacking.
1.3 Research Question and Objectives of Dissertation

To meet the affirming needs of PWDs, a research question is formulated as follow:

_In memory clinics, would the PWDs who receive the use of evidence-based Advance Care Planning intervention have a higher rate of advance directive than those who receive standard practice?_

Objectives of the Study

The objectives of the study are as follows:

1. To review the literatures on the effectiveness of the evidence-based ACP interventions for PWDs

2. To assess the implementation potential of evidence-based ACP interventions for PWDs in memory clinics in Hong Kong

3. To formulate an evidence-based protocol of ACP for PWDs in memory clinics

4. To postulate a measure to evaluate the effectiveness of the evidence-based ACP intervention for PWDs
CHAPTER 2: Critical Appraisal

2.1 Search and Appraisal Strategies

2.1.1 Studies Identification

To facilitate the search for the research evidence, some keywords in relation to the research question were used. There were two main categories for the search. The first category was the “dementia” and “cognitive impairment”, targeting for the research population. The second category was “the advance care planning”, “living wills”, “advance directives”, “end-of-life care” and “palliative care”, concerning the main theme of the research question. Within each category, the synonyms were linked up with ‘or’, while between the categories, the keywords were connected with ‘and’. The same search strategies were used in different databases.

2.1.2 Searching Engines

The search was carried out from 15th April 2014 to 30th April 2014. Three electronic databases- CINAHL Plus, Cochrane Library and PubMed were used. To enrich the research evidence, manual search by reviewing the bibliographic lists of retrieved literatures was performed to explore additional studies.

2.1.3 Selection Criteria

To search for the relevant literatures relating to the research question, the inclusion criteria was used for guidance. The inclusion criteria were the ACP in
relation to dementia with the study design of RCTs and written in English with full
text available. Since euthanasia is illegal and is regarded as unethical in Hong Kong in
view of current legislation and Hong Kong Medical Council's Professional Code and
Conduct for the Guidance of Registered Medical Practitioners (HKLRC, 2006), those
studies relating to euthanasia, assisted suicide or mercy killing were excluded for
complying local situation.

2.1.4 Search Result

The electronic search retrieved a total of 2972 studies from the abovementioned
databases (CINAHL Plus- 274 studies, Cochrane Library- 304 studies & PubMed-
2394 studies). They were preliminary screened by research method of RCTs
(CINAHL Plus- 3 studies, Cochrane Library- 122 studies & PubMed- 52 studies)
before they were further filtered by titles, abstracts and the full contexts in the light of
inclusion and exclusion criteria (CINAHL Plus- 3 papers, Cochrane Library- 4 papers
and PubMed- 4 papers). By further eliminating the replicated studies, 5 studies were
identified finally. Manual search of bibliographic citations of retrieved literatures
yielded 2 additional papers from PubMed (Appendix 1). PRISMA 2009 Flow
Diagram is also used to illustrate the systematic review (Appendix 2).
2.1.5 Data Extraction

Data extraction from the reviewed literatures was done. Tables of evidence were generated (tables 1-7), showing the study type, level of evidence, patient characteristics, interventions, comparison, length of follow up, outcome measures and effect size (Appendix 3-9).

2.1.6 Appraisal and Rating System

To conduct the critical appraisal of the reviewed literatures, a reliable critical appraisal tool- the methodology checklist of critical appraisal for RCTs was adopted from the Scottish Intercollegiate Guidelines Network for the appraisal (SIGN, 2012a). Different scopes of methodology were assessed, covering the internal validity and the overall assessment of the reviewed studies.

To rate the quality of the reviewed literatures, the SIGN grading system was used to conduct the rating, including the levels of evidence (Appendix 10) and grades of recommendation (Appendix 11) (SIGN, 2012b).

2.1.7 Quality Appraisal of the Reviewed Literatures

The summary of the critical appraisal and level of evidence of the reviewed literatures are shown in Appendix 12.
2.1.8 Research Question

The seven reviewed literatures addressed the research questions adequately with the essential elements of PICO but not exactly in the PICO format. They stated their own problems or populations, interventions, comparisons and outcome measures clearly.

2.1.9 Randomization Method

All seven studies stated that they had used randomization method. Ahronheim’s study (2000), however, did not clearly report the randomization method utilized. Griffith III’s study (1995) performed randomization by a random digit-dialing method. Four studies (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012) adequately stated that they used simple randomization by a computer generated scheme, while Sampson’s study (2011) used the same method on ward and individual levels. None of all studies, however, reported the stratifications of randomization in details.

2.1.10 Concealment Method

No concealment was reported in Griffith III’s study (1995). The researchers might overestimate the effect of interventions by up to 40% (SIGN, 2012c). Although Ahronheim’s study (2000) carried out concealment, the details regarding the method were not adequately reported. Nevertheless, five studies (Sampson et al., 2011;
Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012) had adequate concealment since they used the computer-generated allocation method and three of them (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2012) also reported concealment by using numbered envelopes for individual assignments.

2.1.11 Blinding

Only one study, Sampson’s study (2011), adopted blinding method, using double blinding (investigators and subjects) method. Four studies (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012) reported clearly that they did not blind the investigators with explanations given. This might introduce bias to the study results. They did not report any blinding done to the subjects. Griffith III’s study (1995) did not report any blinding done to investigators or subjects, while Ahronheim’s study (2000) had reported blinding to the investigators but it was unclear whether blinding was done for the subjects.

2.1.12 Characteristics of Study Subjects

In four of the reviewed literatures (Ahronheim et al., 2000; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012), the baseline characteristics of the subjects for the control and intervention groups were similar at the beginning of the studies. Volandes’s study (2009b) showed some baseline characteristics differences in
diagnosis of dementia and previous relationship with the PWDs. Volandes’s study (2011) showed differences in baseline characteristics between the intervention group and control group in gender and marital status. The differences for both studies were not statistically significant.

Sampson’s study (2011) had reported the baseline characteristics of the participants (patient-carer dyads) for the groups. Most of the baseline characteristics of the participants were similar. However, there were significant differences in the gender mix of the carers and the relationships of the main carers for the two groups. The intervention group was composed of 64% male carers with a control group of 30%. Besides, the main carers were sons (45%) for the intervention group and daughters (50%) for the control group. These might lead to downgrading the study (SIGN, 2012c).

Griffith III’s (1995) and Volandes’s (2009a) studies did not report the baseline characteristics of the subjects for the groups separately, making them unclear for the similarity of the baseline characteristics of the group subjects. Confounding factors might present, affecting the internal validity of the result findings.

2.1.13 Interventions under investigations

Different interventions were investigated in the reviewed studies. Three studies (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011) had similar
interventions, reading narrative describing advanced dementia based on the FAST stage 7a (threshold for advanced dementia). Thereafter, the subjects watched the video decision support tool or aid by a portable computer. The video described the main salient features of the disease as in the narrative, showing an 80-year-old female patient having advanced dementia with her 2 unreal daughters staying in the nursing home setting. She was shown being unable to respond to the daughters’ attempts in conversation and being pushed in a wheelchair and fed (or hand fed) with pureed food.

Volandes’s (2011) video also included goals of care. The lengths of the videos varied from 2 minutes (Volandes et al., 2009a; Volandes et al., 2009b) to 6 minutes (Volandes et al., 2011). The control subjects only listened to the narratives.

Volandes’s study (2012) used video as an intervention but the content was different. The intervention subjects viewed a 6-minute Goals-of-Care Video (by a portable computer) describing 3 goals of care (life-prolonging care, limited medical care and comfort care) while the control subjects only listened to the narrative with the same goals of care.

The remaining three studies had different interventions. In Ahronheim’s study (2000), the intervention subjects received recommendations shown in table 1 (Appendix 3) by a palliative care team aiming at increasing patient comfort, and control subjects received usual care by a primary care team.
In Griffith III’s study (1995), both group subjects were asked with 16 questions about CPR, Alzheimer’s disease and resuscitation preferences which were extracted from the 1993 Kentucky Health Survey. The intervention subjects listened to a short educational paragraph depicting CPR and chances of surviving resuscitation published by Seckler. Then both group subjects were asked for CPR preferences in 2 scenarios: in their current health state and “if with memory loss and senility (Alzheimer’s) such that your are no longer able to recognize family & friends”.

In Sampson’s study (2011), the carer subjects (both groups) were offered with an information pack. The intervention subjects (carer-patient dyads) were assessed for the palliative care needs of patients (30 minutes): pain, dementia severity, the presence of delirium, communication, pressure sore risk and severity, food and fluid intakes, swallowing and feeding, formulating a management plan and findings to build a framework for discussions of ACP with carers. Discussions were made up with maximum 4 consultations with an interval of at least 5 days. For the first consultation, they assessed the knowledge level about dementia, the severity of dementia & prognosis for the patients, patients’ physical needs, the social situation & current social support levels, records of previous preferences for care. In subsequent consultations, they carried out education for the carers for dementia including disease
nature, prognosis, the roles of palliative care & ACP. The control subjects received usual care.

2.1.14 Outcome Measures

All the seven reviewed studies used reliable measures for the outcomes. In Ahronheim’s study (2000), the outcome measures were mortality; length of stay; number of readmission; use of non-palliative procedures; do-not-resuscitate (DNR) orders & CPR, systemic antibiotics usage; decision making to forgo life-sustaining treatments, antibiotics, intravenous fluids, or blood drawing; decision making to adopt an overall palliative care plan. In Griffith III’s study (1995), Alzheimer’s disease knowledge, CPR knowledge score, CPR preference, correlation between demographic and knowledge variables and decreased preference for CPR in Alzheimer’s disease scenario were used as outcome measures.

In Sampson’s study (2011), the primary outcome was the number of carers involved in making an ACP, while the secondary outcomes (instruments) included the carer distress (KD10), health status and quality of life of carer (EQ-5D), level of carers’ uncertainty and difficulty in decision making (DCS), overall decision satisfaction for carers (DSI), intensity of angry feelings of carers (SAS), life satisfaction of carer (LSQ), life satisfaction being done after patient’s death (SWC-EOLCD) and patient’s pain and distress (VAS).
In Volandes’s study (2009a), the primary outcome measures were goal of care chosen and concordance rate of preferences among patients & surrogates (preferences of care by the elderly and their surrogates predicting patients’ preferences of care chosen according to the substituted judgment criterion). The secondary outcome measures were perceived value of the video in intervention group and advanced dementia knowledge score. For Volandes’s study (2009b), the outcome measures were preferred goals of care immediately after interventions and after 6 weeks- life prolonging care; limited care or comfort care. Meanwhile, in Volandes’s study (2011), the outcome measures were preferred goals of care in advanced dementia, factors associated with a preference for comfort care (age, gender, race, education, marital status, health status, personal history of dementia, previous relationships with a person with advanced dementia, health literacy and randomization group) and the perceived value for the video. Lastly, the primary outcome measure for Volandes’s study (2012) was patients’ preferences for comfort care versus other options and secondary outcome measure was concordance of preferences with documentation in the medical record.

The common outcome measure will be patients’ preferences for goal of care if they are in a state of advanced dementia which can be categorized as 3 options
(life-prolonging, limited or comfort) (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012).

2.1.15 Attrition

According to the notes on methodology checklist for controlled trials from Scottish Intercollegiate Guidelines Network (SIGN, 2012c), it is acceptable for a study with dropout rate up to 20%. Three studies had the dropout rate in the acceptable value, with total 1% dropout (Ahronheim et al., 2000) and 11% dropout for each group (Volandes et al., 2009b) and 0% drop out (Volandes et al., 2009a; Volandes et al., 2011; Volandes et al., 2012). Two studies’ dropout rates were far below the acceptable value, with total 58.2% dropout (Griffith III et al., 1995) and 63.6% dropout for control group & 68.2% dropout for intervention group (Sampson et al., 2011). Sampson (2011) had explained for the high dropout rate being induced by patient mortality and carer withdrawal while Griffith III (1995) did not make any explanation.

2.1.16 Data Analysis

Five studies (Ahronheim et al., 2000; Sampson et al., 2011; Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011) had analyzed the data with intention-to-treat (ITT) method. While Volandes’s study (2012) had all subjects being accounted for and none were lost to follow-up, thus it was not applicable for ITT data analyses.
Griffith III’s study (1995), however, mentioned the use of multivariate analysis for data analysis but did not report the use of ITT, making it at risk of downgrading to a non-randomized cohort study.

**2.1.17 Generalizability of Study**

Three studies (Ahronheim et al., 2000; Griffith III et al., 1995; Volandes et al., 2011) were not multi-site studies, while the other four studies (Sampson et al., 2011; Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2012) did not specify whether marked differences for the sites data exist. Thus, the levels of generalizability of the studies might be lowered.

**2.1.18 Level of Evidence**

In the light of quality assessment, all studies (Ahronheim et al., 2000; Griffith III et al., 1995; Sampson et al, 2011; Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012) achieved the grade of 1+, since the studies adequately fulfilled most of the criteria in the appraisal checklist for RCTs, being regarded as RCTs with a low risk of bias (Appendix 10).

**2.1.19 Length of Follow Up**

The length of follow up differed in the studies. They ranged from 6 months after interventions & 3 months after bereavement in Sampson’s study (2011), 9 months in Volandes’s studies (2009a; 2009b) to 3 years in Ahronheim’s study (2000). Griffith
III’s study (1995) just mentioned it was conducted in June 1993, while Volandes’s study (2011) and Volandes’s study (2012) only mentioned the recruitment periods.

2.2 Summary of reviewed studies

Ahronheim’s (2000) and Sampson’s (2011) studies were conducted in acute hospital settings, while Volandes’s studies (2009a; 2009b; 2011) were conducted in primary care clinics. Griffith III’s study (1995) and Volandes’s study (2012) were conducted in community and skilled nursing facilities respectively.

Only Griffith III’s study (1995) used telephone to conduct the study, concluding the predictors of refusing CPR in scenarios with Alzheimer’s disease as Alzheimer’s disease knowledge or experience with the disease (p< 0.001); older age (p< 0.001); greater income (p< 0.004); female sex (p< 0.01) and nonwhite race (p< 0.04).

Although this study was not directly related to ACPs for the PWDs, it indicated that the education of the disease was significant for deciding DNR in two scenarios (one in Alzheimer’s disease and one in current health state) which in line with Hui’s study (1997), of which supported the significance of disease education on DNR decision.

Thus, this study was included for synthesis of findings.

The other six studies used face-to-face treatments for the interventions. In Ahronheim’s study (2000), it gave recommendations (interventions) by a palliative care team. The admission number and non-palliative procedures usage but not
systemic antibiotics were lower in the intervention group than control group. The
decisions to forgo treatments, including enteral feeds, mechanical ventilation,
intravenous lines, blood draws, antibiotics and CPR, were higher in the intervention
group except the enteral feeds. Besides, more subjects decided to make palliative care
plan in the intervention group (22.9% vs 3.9%, p=0.008), indicating the
recommendations were overall effective. The plans were adopted, however, until
discharge.

In Sampson’s study (2011), the investigators offered an information pack to
carers. Then they performed the comprehensive assessment of patients’ palliative care
needs and the discussion for ACP with carers comprise up to 4 consultations (at least
5 days apart). The first consultation was assessment while subsequent consultations
were education for the carers. For the intervention group, 7 out of 22 carers (32%) had
made ACPs. Although the effect size was small, none of the carers in the control
group had made any ACP. Thus, the interventions still increased the adoptability of
ACP.

The remaining three studies (Volandes et al., 2009a; Volandes et al., 2009b;
Volandes et al., 2011) had similar interventions, reading narrative describing dementia
based on the FAST stage 7a (Appendix 13) and broadcasting a video decision support
tool or aid which showed the salient features of advanced dementia by a portable
computer, but Volandes’s (2011) video also included goals of care and the length of the video ranged from 2 minutes (Volandes et al., 2009a; Volandes et al., 2009b) to 6 minutes (Volandes et al., 2011). The results (Volandes et al., 2009a; Volandes et al., 2009b) showed that more subjects in the intervention group preferred comfort care as goal of care (100% vs 50% & 86% vs 64%), less preferred limited care (0% vs 17% & 9% vs 19%) or life prolonging care (0% vs 33% & 4% vs 14%), while Volandes’s study (2009b) also showed intervention subjects had less uncertainty for preferences (1% vs 3%) (P= 0.003) and 22 % difference for choosing comfort care (95% CI, 11% to 34%, p<0.001). This is consistent with the results of Volandes’s study (2011), showing that the intervention subjects were more likely to choose comfort care instead of life-prolonging or limited care (life-prolonging care; limited care; comfort care: 0%; 9%; 91% vs 16%; 12%; 72% with $\chi^2= 6.3$, df= 2, p= 0.047).

In Volandes’s study (2012), the subjects viewed a 6-minute Goals-of-Care Video describing 3 goals of care. The intervention subjects were more likely to choose comfort care and less likely to choose life-prolonging with less uncertainty (comfort; limited; life-prolonging; uncertain: 80%; 8%; 12%; 0% vs 57%; 8%; 33%; 2%) Being randomized to the video group was associated with greater chance of opting for comfort (unadjusted rate ratio, 1.4; 95% CI, 1.1to1.9, p = 0.02).
All seven reviewed studies’ methodologies were RCTs, but one should note that Volandes’s study (2012) was the study protocol of a Goals-of-Care video for elderly patients admitted to skilled nursing facilities. Since the study took place in institutional setting which was different to the settings of other reviewed studies, Volandes’s study (2012) was included for synthesis of findings to add more evidence to the research question.

2.3 Synthesis of findings

Critical appraisal was done for the seven most relevant literatures, contributing to the fruitful and high level of evidence to the research question. Main themes were generated to synthesize the findings as follows:

2.3.1 Period and duration (time)

The ACP discussions should make up of maximal 4 sessions with at least five days apart (Sampson et al., 2011). The decision video tool/aid should last for about 2 to 6 minutes (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012).

2.3.2 People

The PWDs should make an ACP in the earlier stages of the disease since they are still able to discuss the issues and actively participate in the decision making for their
future care (Sampson et al., 2011; Volandes et al., 2009b). Thus, they should make the ACPs with mild to moderate stages of dementia.

Three studies (Ahronheim et al., 2000; Sampson et al., 2011; Volandes et al., 2009a) suggested the ACP process should involve the patients and carers/surrogates. While three other studies (Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012) suggested to involve the patients only. The current evidence suggested that former approach should be adopted to ensure the implementation of the patient wishes conveyed by AD, because this increases the concordance of goals of care for PWDs and their carers (Volandes et al., 2009a) and minimizes disputes raised by the carers regarding the AD which may lead to proceedings to the court (FHB, 2009).

Personnel conducting the interventions should be a senior nurse experienced in dementia with training in palliative care (Sampson et al., 2011) or a clinical nurse specialist with master degree and rich experience in advanced dementia (Ahronheim et al., 2000).

2.3.3 Place for the intervention

The intervention should be delivered face-to-face (Ahronheim et al., 2000; Sampson et al., 2011; Volandes et al. 2009a; Volandes et al. 2009b; Volandes et al., 2011; Volandes et al., 2012) and should be done in a quiet room in the clinic area
2.3.4 Content

The ACP sessions should be composed of some crucial components, including an information pack about advanced dementia, ACP and palliative care definition (Sampson et al., 2011). A video aiding the ACP decision, of which depicting the advanced dementia (appendix 14) and goals of care, should be broadcasted to the PWDs and their carers (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012). The education for the disease knowledge is also supported by Griffith III’s study (1995) which showed that Alzheimer’s disease knowledge as a predictor of refusing CPR (p< 0.001) and knowledge about the disease increased by video education (Volandes et al., 2009a; Volandes et al., 2009b). The goals of care should be conveyed by written medical record such as AD to ascertain PWDs’ preferences (Volandes et al., 2012).

After having critical appraisal of the seven reviewed studies, sufficient evidence is shown to the ACP intervention for PWDs. The potential to implement the ACP intervention for PWDs in a memory clinic in Hong Kong will be explored, including the transferability of the findings, feasibility of the ACP intervention and the cost & benefit ratio.
Chapter 3: Translation and Application

3.1 Introduction

In the previous chapter, the ACP for PWDs has been critically appraised. In this chapter, the implementation potential for the ACP intervention for PWDs in a local MC will be explored, including the transferability of the findings, feasibility and the cost & benefit ratio.

3.2 Target Setting & Audience

MCs are clinics targeted for PWDs to slow down the deterioration of cognitive function, ADL or IADL of PWDs. They provide support to their relatives (JCCPA, 2014). MCs seldom develop, however, future planning of health care for PWDs. Thus, target audience of the protocol includes the administrators (general manager and service manager) and health care professionals (geriatrician and nurses) working in MCs.

3.3 Transferability of the Findings

Transferability is defined as the extent of the research findings being transferable or applicable to other settings or groups (Polit & Beck, 2012). The following sections discuss the transferability of the ACP intervention to MCs.

3.3.1 Comparability of target setting and audience

As mentioned in previous chapter, Ahronheim’s (2000) and Sampson’s (2011)
studies were conducted in acute hospital settings while Volandes’s studies (2009a; 2009b; 2011) were conducted in primary care clinics, Griffith III’s study (1995) and Volandes’s study (2012) were conducted in community and skilled nursing facilities respectively.

In the light of different settings, this increased the confidence of generalizability to the proposed setting. Similar to the population mentioned in Volande’s (2009b) study, the clients coming to the MCs were PWDs with the mild to moderate stages of dementia. This makes the proposed implementation transferrable to the MCs. Besides, the PWDs with acute illness staying in acute setting were inappropriate for the intervention. While the primary care clinic nurses are not as experienced in dementia as the MCs nurses, of which is the personnel requirement as stated in the literatures (Ahronheim et al., 2000; Sampson et al., 2011). Thus, MC is chosen as target setting.

3.3.2 Philosophy of care

The philosophy of care for the MC is that they believe the PWDs are as treasurable as other aging population and they should be respected. It is in line with the philosophy of care underlying the ACP intervention which preserves and respects their autonomy and human dignity through empowering them to execute their self-determination for the choices of care by writing the ADs through the ACP.
3.3.3 Sufficient number of clients to be beneficial from the proposed ACP intervention

The targeted MC has cumulated 380 clients in active status and a new client comes in each weekly session. There are sufficient clients (about 159 clients annually) who can take benefits from the proposed ACP intervention.

3.3.4 Timeframe for the implementation

The whole period of ACP intervention takes 16 months, including preparatory, intervention and evaluation phases (Appendix 15).

3.4 Feasibility

3.4.1 Autonomy of nurses to carry out or terminate the proposed ACP intervention

The MC ultimate decision-makers are service manager and general manager. They welcome nurses to propose ACP intervention if it is doing something good to the clients. The nurses can actively report to them on any undesirable result of the proposed ACP intervention and request termination. Thus, they have freedom, to certain extent, to carry out and terminate the ACP intervention.

3.4.2 Interference with current staff functions

Resistance to the proposed ACP intervention should be figured out. The major potential resistance may come from the nurses (not the pioneer nurse) in the MC. They may worry about the extra workload and feel incompetent for the change. Actually, it will not interfere with current staff works. They participate in the
intervention within the office hour. Besides, a 30-minute introductory briefing
session on the intervention and a 3-hour training session will be given in order to
increase their understanding and confidence of competency to the proposed ACP
intervention. Additional training sessions will be provided after pilot testing.

3.4.3 Administration support

Although the resistance to the proposed ACP intervention is minimized, there
may be limited friction caused by the implementation. For instance, the pioneer nurse
needs the help of the training & promotion team to liaise with the video production
and the friction may rise here. Thus, administration support is crucial and has been
gained before implementing the proposed ACP intervention.

3.4.4 Availability of skills and facilities

Two nurses in MC are both experienced in dementia for at least ten years and
have completed postgraduate study, of which complied with the eligibility for the
personnel conducting the intervention. Also, MC has the equipment and facility
required for the proposed ACP intervention - video player and a quiet room in the
clinic.

3.4.5 Availability of evaluation tools

Descriptive evaluation will be used as a clinical evaluation of the intervention.
The primary outcome measure will be the number of PWDs making an AD.
Secondary outcome measure will be preferred goals of care immediately after intervention if in a state of advanced dementia (life-prolonging, limited or comfort care) (Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012), the perceived value of the video in intervention group (a 4-point Likert scale) (Volandes et al., 2009a) and the rating for the satisfaction towards the intervention of the nurses (a 5-point Likert scale).

3.5 Cost-benefit Ratio of the Intervention

3.5.1 Potential risks

All of Volandes’s studies (2009a; 2009b; 2011; 2012) reported no adverse events for both control and intervention subjects in these studies. Clients will not be exposed to risks in the intervention.

3.5.2 Potential benefits

Numerous potential benefits could derive from the intervention. PWDs can preserve their autonomy and human dignity through the ACP, executing their self-determination for the health care choices when being incapacitated in the future and increasing their EOL care. Moreover, the concordance between the clients and their surrogates will be increased through ACP, minimizing any dispute raised with the carers regarding the AD.
3.5.3 Material costs

The material cost is about $20,117 for 18 potential clients in pilot and it is about $21,033.5 for 159 potential clients (pilot and long run) (Appendix 16). No additional staff has to be recruited for the intervention. The staff cost has already been covered by the centre daily operation.

3.5.4 Material benefit and cost/benefit ratio

Since MC has a room and video broadcasting machine for intervention, no additional cost is required. The video production will be done by the Hong Kong Federation of Youth Groups Jockey Club Media 21 (2015). It charges the video production with $20,000. 3 video hard copies in DVD format and a soft copy will be provided. Actors will be the staff and volunteers being recruited from the centre. Cost of the actors will be free of charge. The pioneer will apply for the venue in QMH through the Communication Relations Office. No material cost of not implementing the proposed ACP intervention is noted.

The potential non-material costs of implementation may include lowered nursing staff morale and absenteeism, because their worry for increasing workload may not be released by the briefing session. While the potential non-material benefit of implementation is improving the image of both the centre and the MC since this proposed ACP intervention has not been implemented in the MCs locally.
Chapter 4: Developing an Evidence-based Practice Guideline

This guideline is based on the guideline developed by the Scottish Intercollegiate Guidelines Network (SIGN, 2014). The handbook acts as a reference tool for the development of the protocol, assisting grading the evidence for the seven reviewed studies (Ahronheim et al., 2000; Griffith III et al., 1995; Sampson et al., 2011; Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012). All seven studies got the level of evidence 1+ (SIGN, 2012b). The flow chart (Appendix 17) shows the work flow of ACP intervention in MC.

4.1 Title of the Guideline

An Evidence-based guideline of using ACP intervention to increase the rate of formulated AD for PWDs in MCs.

4.2 Objectives of the Guideline

The specific objectives of the guideline are:

1. To summarize the clinical evidence for the use of ACP intervention to increase the rate of formulated AD for PWDs in MCs.

2. To generate clinical instructions for nurses to use ACP intervention solid on the body of existing evidence.

3. To standardize the use of ACP intervention for PWDs.


4.3 Intended Users

Nurses working in MCs are the intended users of the guideline.

4.4 Target Population of the Guideline

The target population is PWDs with mild to moderate stages of dementia.

4.5 Rating Scheme for the Strength of the Recommendations

The SIGN grading system was used to conduct the rating, including the levels of evidence and grades of recommendation (Appendix 10&11) (SIGN, 2012b).

4.6 Recommendations

4.6.1 People

1. The PWDs should make ACPs in the earlier stages of the disease since they are still able to discuss the issues and actively participate in the decision making for their future care. Thus, they should make the ACPs with mild to moderate stages of dementia.

Grade of recommendation: A

Available evidence:

- PWDs should consider making an ACP when in the earlier stages of the disease as they have the ability to discuss such issues and can be more actively involved in making future care choices (Sampson et al., 2011).
Patients in the early stages of dementia can affect the treatment will be received by exploring their goals of care with their physician (Volandes et al., 2009b).

2. The ACP process should involve the patients and carers/surrogates.

Grade of recommendation: A

Available evidence:

- Family caregivers or other surrogates would be met by the palliative care team when they were available (Ahronheim et al., 2000).
- The intervention included a palliative care patient assessment which informed an ACP discussion with the carers being offered the opportunity to write an ACP for PWDs (Sampson et al., 2011).
- Concordance rate of the patient goal of care is higher for patients and surrogates viewing a video decision-support tool for advanced dementia than listening to a verbal description of the disease (Volandes et al., 2009a).
- To minimize dispute raised with the carers regarding the AD, of which may lead to proceed to the court for a decision (FHB, 2009).

3. Personnel for conducting the interventions should be an experienced nurse who has experience in dementia and being trained with palliative care or a clinical nurse specialist with master level and rich experience in advanced dementia.
Grade of recommendation: A

Available evidence:

- A senior nurse experienced in dementia and being trained with palliative care would deliver the intervention (Sampson et al., 2011).

- The palliative care team consisted of a clinical nurse specialist with master level and rich experience in advanced dementia (Ahronheim et al., 2000).

4.6.2 Period and duration (time)

1. The ACP discussions should be made up of maximal 4 sessions of which should be at least five days apart.

Grade of recommendation: A

Available evidence:

Component 2 of the intervention included discussions with carers with up to 4 consultations (>=5 days apart) being offered to carers (Sampson et al., 2011).

2. The decision video tool/aid should last for about 2 to 6 minutes.

Grade of recommendation: A

Available evidence:

- The subjects listen to the verbal narrative followed by watching a 2- minute video which describes a patient with advanced dementia (Volandes et al., 2009a).
• The subjects listen to the verbal narrative followed by watching a 2 minute video which describes a patient with advanced dementia (Volandes et al., 2009b).

• The subjects watch a 6-minute Goals-of-Care video decision aid depicting salient features of advanced dementia and the goals of care by a portable computer (Volandes et al., 2011).

• The subjects viewed a 6-minute Goals-of-Care video by a portable computer describing 3 goals of care (Volandes et al., 2012).

4.6.3 Place for the intervention

1. The intervention should be done in a quiet room in the clinic area.

Grade of recommendation: A

Available evidence:

• A trained member of the research team collected all data in a quiet room in the clinic area (Volandes et al. 2009a).

• Data was collected by a trained member of the research team in a quiet room in the clinic area (Volandes et al., 2009b).

• A trained member of the research team collected all data were in a quiet room in the clinic area (Volandes et al., 2011).
A trained member of the research team presented the video and verbal narratives to the subjects in a quiet room in the SNF (Volandes et al., 2012).

4.6.4 Content

1. The ACP sessions should compose of some crucial components, including an information pack about advanced dementia, ACP and palliative care definition.

Grade of recommendation: A

Available evidence:

- Carers in both groups were offered an information pack, including an information sheet from the UK Alzheimer’s Society on advanced dementia, a leaflet on advance care planning and one giving a simple definition of palliative care (Sampson et al., 2011).

2. A video aiding the ACP decision, of which depicting the advanced dementia and goals of care, should be broadcasted to the PWDs and their carers.

Grade of recommendation: A

Available evidence:

- Concordance rate regarding patient’s end-of-life preferences is higher for the subjects viewing a video decision support tool for advanced dementia than those only listening to a verbal description of the disease (Volandes et al., 2009a).
• Older people who view a video depiction of a patient with advanced dementia after hearing a verbal description of the condition are more likely to choose for comfort care when compared with those who only listen to a verbal narrative. Besides, the preferences of care are more stable over time (Volandes et al., 2009b).

• Subjects viewing a goals-of-care video decision aid were more likely to choose comfort care when compared with those only listened to a verbal narrative (Volandes et al., 2011).

• Subjects admitted to SNFs who viewed a Goals-of-Care Video were more likely to choose comfort care than those listened to a verbal narrative (Volandes et al., 2012).

3. Education about dementia knowledge is supported by video education.

Grade of recommendation: A

Available evidence:

• Griffith III’s study (1995) showed that Alzheimer’s disease knowledge as a predictor of refusing CPR (p< 0.001).

• Knowledge about advanced dementia was increased by video education (Volandes et al., 2009a).

• Knowledge about advanced dementia was increased by video education
(Volandes et al., 2009b).

4. The goals of care should be conveyed by written medical record such as advance directives to ascertain PWDs’ preferences.

Grade of recommendation: A

Available evidence:

- A lack of correlation between documented DNR status and stated preferences for comfort care, regardless of decision-making modality, was shown in the findings (Volandes et al., 2012).

By examining the intended users and target population of the guideline, the recommendations and its strength, an evidence-based practice guideline including people, time, place and content of ACP intervention for PWDs in MCs has been developed and it is now ready for implementation.
Chapter 5: Implementation and Evaluation

In the previous chapter, the implementation potential for the proposed ACP intervention in a MC has been assessed and the evidence-based practice guideline has been developed. In the following, details of the implementation and evaluation plans will be explored to transfer the guideline into the daily operation of the MC.

5.1 Communication plan

5.1.1 Involvement of stakeholders

Stakeholders for this proposed ACP intervention include the staff (general manager, service manager, the doctor and nurses running the MC) in the targeted MC, all local memory clinics, PWDs and their relatives.

5.1.2 Development of communication team

The proposed ACP intervention pioneer will form a communication team to facilitate the communication and implementation process with the staff in the centre. It includes the general manager, service manager and the pioneer nurse. They will hold meeting bi-weekly, reviewing the proposed ACP intervention progress, making it more sustainable.

5.1.3 Communication process and implementation strategies

Communication process between the project team and the staff in the centre is a milestone for the success of transferring the guideline into practice. At the
pre-implementation stage, the pioneer nurse presents the proposal, highlighting the evidence for the affirming need of implementation and details of the implementation process such as the resource and manpower needed to the managerial staff.

Thereafter, the pioneer nurse will form a working group which includes the pioneer nurse, the doctor and two nurses in the MC. They are the experienced professionals in dementia care. Moreover, they are the guideline end users, they can feedback for it instantly, helping to fine-tune it continuously during the implementation.

A marketing communication model- attention, interest, desire, action (AIDA) can be used to assist the project team to develop the guideline (Kam, 2010). Its first goal of product launching is to grab people attention for the product such as appealing by celebrity. Then it has to hold people interest and create their desire for the product by means of product features promotion. It ends with the purchase action. Thus, the project team has to grab the attention from the managerial staff by using interactive and fruitful presentation and raise their interest to know more about the guideline and desire to take action i.e. agreement for the guideline implementation. This model is used throughout the communication process between the communication team, the project team and other staff.

Thereafter, the pioneer nurse will give a briefing session internally to the
project team members, so that they can fully understand the implementation. Then she will give a 3-hour training session about the guideline precisely to the nurses.

Additional training sessions will be given after pilot testing.

5.2 Pilot study plan

Commencement of pilot study is warranted since it can test the actual feasibility of the guideline in the local setting. It will take a month. The users will have buffering time to adapt to the change of current practice. Besides, it actualizes the guideline and the problems such as logistics may give rise. It allows the project team to amend it, making it more practical in MC.

5.2.1 Client enrolment strategies

The pilot will enroll 18 clients potentially. The client enrolment will follow the inclusion and exclusion criteria of the guideline. The pioneer nurse will be in charge of the recruitment process of pilot study, ensuring the compliance of the inclusion and exclusion criteria and consistency of the clients recruited. Besides, MC nurses will assist the recruitment procedure, so as to get familiar with the recruitment procedure for long term run.

5.2.2 The ACP for PWDs guideline

The ACP for PWDs guideline gives a clear guidance for the users to implement the evidence-based practice of ACP for PWDs in MC. A hard copy will be
put in the nurse station of MC for quick reference. A soft copy will be available in the public folder of the centre computer system, of which is accessible by the centre staff. There will be an additional file attached, explaining some common questions regarding the guideline and a feedback corner for staff to reflect their opinions.

5.2.3 Logistics

During the pilot study, the workflow, time period, manpower and budget will be assessed. The project team should prepare a detailed road map for the preparatory, implementation and evaluation phases. It will schedule the timeframe of different phases, the meetings and training for different parties, materials preparation (preparation for video production and ACP materials-ACP information packs, AD forms and hard copies of guideline), ensuring the actions and communications are taken as planned. Logistics testing in the pilot period can fine tune the full intervention.

5.2.4 Data collection method

Data collection will be performed by a research assistant. This minimizes introducing bias to the pilot study. Demographic data such as gender, age, race, education, marital status, health status, personal history of dementia will be collected. Past health history and data about the dementia knowledge will also be collected. All data will be keyed into the database by the data collector to minimize error.
5.2.5 Post pilot study plan

After completing the pilot study, all the information will be analyzed by the research assistant. Soon thereafter, the communication team and project team will hold a meeting to discuss the pilot study result and make amendment and the logistics for the guideline.

5.3 Evaluation plan

5.3.1 Outcomes to be assessed

There will be three scopes of outcome to be evaluated, including patient outcomes, healthcare provider outcomes and system outcomes. For patient primary outcome, it assesses the clinical benefits of the proposed ACP intervention for the clients. In this proposed ACP intervention, patient outcome is the number of PWDs making an ACP. It looks for how many PWDs will make an AD after having the intervention according to the evidence-based guideline. The secondary outcome for patient will be the preferred goals of care immediately after interventions, the patient chooses either life prolonging care, limited care or comfort care if in advanced stage of dementia. After delivering the evidence-based practice of ACP for PWDs, the PWDs will proceed to make ADs in accordance with their willingness. The AD will be made under the witnesses of the geriatrician and their carers/ surrogates. The three parties have to sign the AD forms to make the forms effective. Another secondary
outcome for patient is perceived value of the video.

Healthcare provider outcome is the acceptance of the nursing staff towards the intervention, it will be reflected by the nurses’ satisfaction to the intervention. This outcome is crucial because if the users (nurses) are not satisfied with the intervention, they will have low initiative to participate the intervention, making the intervention not sustainable in the long run. Besides, there may be increase of sick leave or turnover rate due to low morale if they are not satisfied with the new change or extra work load being perceived. This induces a chain reaction that the administrative staff may not support for the long term running of the intervention.

The system outcome is the cost of the intervention. From the administration point of view, introducing evidence-based guideline will increase the quality of service provided by the centre which in turn increasing the reputation of the centre. If the intervention is too expensive which cannot outweighs the benefits resulting from the intervention, the administrative staff may not consider the long term running of the proposed ACP intervention due to limited budgets and resources of the centre.

Although there are many outcomes in the three main areas, the major outcome will be the patient outcomes in this ACP intervention.

5.3.2 Timing and frequency of taking measurements

The study will make use of longitudinal design. For patient outcome data, the
data will be collected at four points- 0, 1, 6 and 12 months. The research assistant will collect the data prospectively at each point. This is chosen since the centre runs the MC weekly and the study would evaluate the accumulative number of PWDs making an ACP. This is time saving and resource saving. Moreover, the PWDs may change their preferred goals of care overtime and has right to have revocation of AD. Shorter period of timing of taking measurements at the beginning (1 month) allows the study to see the initial stability of PWDs preference of goals of care and ACP status. Too frequent data collection, however, cannot examine the changes obviously and will also waste resources. Thus, the following measurements takings are fixed as 6 months and 12 months. Setting the timeframe as a year for the end of data collection would provide enough time to allow changes to happen. This also complies with the length of follow up with a year as suggested by the majority of reviewed studies (6 out of 7).

A time table shown as a Gantt chart provides a clear timeframe, guiding each stage of the implementation (Appendix 15).

For the healthcare provider and system outcomes, the data will be collected quarterly- 3, 6, 9 and 12 months. This timing of taking measurements is long and at regular interval one, since the level of satisfaction to the proposed ACP intervention by the healthcare provider overtime and intervention cost will not be changed vigorously. This will be more cost effective.
5.3.3 Nature and number of clients to be involved

The nature of clients to be involved will be consistent with the guideline. They will be the PWDs in the earlier stages of the disease (mild to moderate stages of dementia), since they are still able to discuss the issues and actively participate in the decision making for their future care. Besides, the PWDs with severe hearing or visual impairment will be excluded because they cannot fully participate in the intervention. The PWDs without carers/ surrogates will also be excluded from the intervention as the evidence-based guideline indicates the ACP process should involve both the PWDs and their carers/ surrogates.

The client recruitment process will make use of convenience sampling method. The design of the study will be quasi-experimental. Chi-square test will be performed for each follow-up visit. A p-value <5% will be used to show statistical significance. The effect size will be 30% of clients making ADs with the Power 80% and Df 5. By performing chi-square test using the statistical power analyses tool- G*Power version 3.1.9.2 (Faul et al., 2014), sample size of 143 is obtained. The attrition rates range from 0 to 11% in the reviewed studies (Ahronheim et al., 2000; Volandes et al., 2009a; Volandes et al., 2009b; Volandes et al., 2011; Volandes et al., 2012). The high attrition rates by Griffith III et al. (1995) and Sampson et al. (2011) will be excluded since the former was the study conducted by telephone and the latter study subjects were in
advanced stage of dementia, differing from this implementation. Thus, the attrition rate will be taken as 11% conservatively. As a result, the actual sample size will be 159. There are sufficient clients (about 432 clients annually) in the MC, so it is achievable to get enough sample size for the proposed ACP intervention.

5.3.4 Analysis of data

The major evaluation outcome will be the percentage change of total number of PWDs making an ACP. The analysis method will be significance testing. Chi-square test will be performed. For the patient outcome - the preferred goals of care (life-prolonging care, limited medical care and comfort care), univariate analyses by using $\chi^2$ test will be performed used for data analysis, comparing the preferences between the control and intervention groups. The degree of freedom and p-value will also be reported. For another patient outcome, the perceived value of the video (a 4-point Likert scale: very helpful; somewhat helpful; very comfortable or somewhat comfortable) will be analyzed with the mean and SD being reported.

For the healthcare provider outcome data, the rating for the satisfaction towards the intervention of the nurses (a 5-point Likert scale: strongly agree; agree; neutral; disagree or strongly disagree) will be analyzed. The mean and SD will be reported.

For the system outcome data- the cost of implementation will be calculated.
The demographic data will be described by descriptive statistics. The SPSS software will be used for the statistical analyses.

5.3.5 Determination of evidence-based guideline effectiveness

The key determinant of the effectiveness for the evidence-based guideline is the statistically significant increase for the number of ADs made by the PWDs in the MC after having received the intervention.

Greater proportion choosing comfort care as the goal of care also reflects their understanding towards advanced stage of dementia, indicating that the guideline is effective. Besides, the high rating for the perceived value of the video indicates that the tool used in the guideline is an effective one.

On the other hand, the high satisfaction towards the intervention by the health care providers, of which improving the staff morale, will also show the guideline being effective. If the benefits resulting from the change are shown while the cost of the implementation is reasonable and controllable at the same time, the guideline is also considered as effective.

5.4 Ethical consideration

By considering ethical issue, all the clients enrolled will be provided with the intervention. No control group is made. It will be considered as unethical that not providing the available ACP intervention, leading the PWDs in control group being
divested of the right to have a process of learning and considering for the options of
decisions for their future care. There is no patient harmful act due to the new practice
because there is no adverse event resulting from the intervention as described by the
reviewed literatures.

All the data collected, including the patient personal data, will be kept as
confidential and only be accessible by authorized persons, including pioneer nurse,
research assistant, the geriatrician and nurses in the MC.

After having discussed the details of the implementation and evaluation plans,
the evidence-based protocol of ACP for PWDs in MCs is now ready for use.
Chapter 6: Conclusion

Dementia is an irreversible and progressive disease of the brain, rendering the PWDs in advanced stage of dementia being incapable of expressing for themselves. Moreover, many surrogates or relatives of the PWDs justified the care and life-sustaining treatments from their own perspectives instead of using substituted judgment with patients’ known wishes in my clinical experience. From my observation in the acute setting, this phenomenon results in the death of PWDs with poor EOL care, losing their dignity and autonomy. It is too late to initiate ACP interventions in the secondary and tertiary settings. Interventions facilitating the ACP earlier for the community-dwelling PWDs, however, are still lacking. Thus, it triggered my desire to prepare this dissertation.

In this dissertation, I have affirmed the need and significance of ACP intervention for PWDs in MCs. Thereafter, I have performed databases searching and critical appraisal of up-to-dated literatures. After synthesis of findings, exploring the translation and its application, conducting implementation plan and evaluation plan, the evidence-based guideline of ACP for PWDs in MCs has been generated.

It is plausible that this evidence-based guideline will elicit introduction of the proposed ACP intervention in local settings. Although the proposed ACP intervention is very new to stakeholders, the fact that benefits of implementing the proposed ACP
intervention outweighing the cost and ample evidence shown in this dissertation will create their desire to introduce this new practice in their settings. The settings for this ACP intervention are not limited to MCs. Instead, it may also be used in other community settings such as geriatrics day care centres and elderly health centres. Future works has to be done to explore and extend the implementation of ACP intervention for PWDs in different elderly community settings.

The impact of dementia is not only limited to the PWDs, but also to their caregivers and families. A recent study shows that there is an association among family caregivers’ abusive behaviors, dementia peoples’ agitated behaviors and caregivers’ symptoms of burnout (Yan, 2014). Early ACP intervention does relieve caregivers’ stresses when handling the end-of-life issues of their beloved PWDs.

Moreover, dramatic increase of dementia does put a great economical impact or burden nationally and internationally. It is estimated the total worldwide costs of dementia were US$ 604 billion in 2010 (Alzheimer’s disease International and World Health Organization, 2012). Mortality due to dementia is also in an increasing trend in Hong Kong. More than doubling for the number of deaths are attributable to the disease of dementia among people aged 60 and above for the period between 2001 and 2009. Mortality rates for dementia have also increased in Hong Kong. In 2006, about 286,313 Disability-Adjusted Life Years DALYS were lost by dementia (Yu et
al., 2012). The mortality for dementia is within top 10 for the number of Registered
Deaths by Ten Leading Causes of Death in 2012 in Hong Kong, ranking 9
(Department of Health, 2013). Early ACP intervention will help to relieve the
economical burden of Hong Kong government.

For the sake of the quality of life for PWDs, psychosocial well beings of
PWDs’ carers and the economical burden of the government, the administrators and
healthcare professionals serving PWDs should not hesitate to introduce the proposed
ACP intervention to their settings.
## Appendix 1

### Search Strategies

<table>
<thead>
<tr>
<th>Key Words Search</th>
<th>CINAHL Plus</th>
<th>Cochrane Library</th>
<th>PubMed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dementia OR cognitive impairment</td>
<td>8910</td>
<td>7660</td>
<td>175797</td>
</tr>
<tr>
<td>2. Advance care planning OR living wills OR Advance directives OR end-of-life care OR palliative care</td>
<td>7232</td>
<td>3264</td>
<td>100177</td>
</tr>
<tr>
<td>Combine 1 &amp; 2</td>
<td>274</td>
<td>304</td>
<td>2394</td>
</tr>
<tr>
<td>Screening with Randomized Control Trials</td>
<td>3</td>
<td>122</td>
<td>52</td>
</tr>
<tr>
<td>Manual Screening of the titles &amp; full texts with inclusion &amp; exclusion criteria</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Filtering out replications</td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Manual search of bibliographic citations of retrieved literatures</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Total studies retrieved</td>
<td></td>
<td></td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix 2

Records identified through database searching (n = 2972)

Additional records identified through other sources (n = 2)

Records after duplicates removed (n = 1764)

Records screened (n = 177)

Records excluded (n = 1587)

Full-text articles assessed for eligibility (n = 7)

Full-text articles excluded, with reasons (n = 0)

Studies included in qualitative synthesis (n = 0)

Studies included in quantitative synthesis (meta-analysis) (n = 7)
Table of evidence (Table 1):

<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence (Control / Intervention)</th>
<th>Patients characteristics (Control / Intervention) (n= 48)²</th>
<th>Intervention(s)</th>
<th>Comparison (n= 51)²</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size (Control group/ Intervention group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ahronheim et al. (2000)</td>
<td>RCT (1+)</td>
<td>Mean age: 85.6/ 83.9 year Female: 44/ 37 Days in hospital: 6.7 ± 7.6/ 9.0 ± 11.7 Race (black; white): 19; 18/ 20; 18 Dementia stage¹ (6d-7b; 7c-7f): 21; 30/ 26; 22 Residence (home; nursing home): 13; 38/ 16; 32 Advance directives(any advance directive; living will; healthcare proxy; oral): 7; 0; 5; 3 / 8; 5; 4; 3 Feeding tube present: 12/12 Discharge diagnosis (pulmonary; other infection; GI; cerebrovascular; cardiac; other): 43; 15; 10; 4; 2; 24/ 40; 11; 13 ;2; 5; 21</td>
<td>Subjects received recommendations by a palliative care team aiming at increasing patient comfort, which include: avoiding non-palliative procedure &amp; mechanical restraints; receiving pain medication for painful maneuver like ulcer debridement or other medications for symptoms control; rehabilitation methods like positioning methods, massage therapy, contractures prevention; counseling of surrogate &amp; care providers about patient’s rights &amp; surrogates duties as decision makers; alternate care planning like forgoing life-sustaining treatments, discharge to hospice or discharge with palliative care plan &amp; avoiding readmission</td>
<td>Subjects received usual care by a primary care team without the recommendations in the intervention group</td>
<td>3 year</td>
<td>1. Mortality 2. Length of stay 3. Number of readmission 4. Use of non-palliative procedures 5. Do-not-resuscitate orders &amp; cardiopulmonary resuscitation , systemic antibiotics usage 6. Decision making to forgo life- sustaining treatments, antibiotics, intravenous fluids, or blood drawing 7. Decision making to adopt an overall palliative care plan</td>
<td>1. Mortality: 24.5 %/ 25% 2. Length of stay: 9.7/ 8.8 3. Number of admissions: 98/92 4. Number of patients who use non-palliative procedures (new feeding tube; total feeding tube; mechanical ventilation; tracheostomy; CPR; systemic antibiotics): 22; 34; 4; 1; 3; 69/ 22; 34; 2; 0; 73 5. Decisions to forgo treatment (enteral feeds; mechanical ventilation; intravenous lines; blood draws; antibiotics; CPR in hospital; CPR nonhospital): 7.8%; 0%; 1%; 0%; 0%; 64.3%; 38.8%/6.3%; 6.3%; 10.4%; 8.3%; 6.3%; 67.4%; 51.1% 6. Decision to make palliative care plan: 3.9%/ 22.9% (p=0.008)</td>
</tr>
</tbody>
</table>

1. Functional Assessment Staging Tool (FAST). 2. n= number of subjects
<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence</th>
<th>Subjects characteristics (N=661)¹</th>
<th>Intervention(s) (n= half of N)²</th>
<th>Comparison (n= half of N)²</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size (Control group/ Intervention group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Griffith III et al. (1995)</td>
<td>RCT (1+)</td>
<td>Age in year: 18-33 (22%); 34-49 (35%); 50-65 (25%); &gt;65 (19%)</td>
<td>1. Asking 16 questions about CPR, Alzheimer’s disease &amp; resuscitation preferences in the 1993 Kentucky Health Survey</td>
<td>June 1993</td>
<td>Knowledge of Alzheimer’s disease( 0-4)</td>
<td>-subjects scored 3.3±1.0 for Alzheimer’s disease knowledge</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sex: F- 57%; M-43%</td>
<td>2. Asking subjects for CPR preferences in 2 scenarios: in their current health state and “if with memory loss and senility (Alzheimer’s) such that you are no longer able to recognize family &amp; friends”</td>
<td>2. Asking 16 questions about CPR, Alzheimer’s disease &amp; resuscitation preferences in the 1993 Kentucky Health Survey</td>
<td>2. CPR knowledge score (0-5)</td>
<td>-subjects scored 1.9±1.3 for CPR knowledge</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Race: 93% white</td>
<td>2. Asking subjects for CPR preferences in 2 scenarios: in their current health state and “if with memory loss and senility (Alzheimer’s) such that you are no longer able to recognize family &amp; friends”</td>
<td>3. Asking subjects for CPR preferences in 2 scenarios: in their current health state and “if with memory loss and senility (Alzheimer’s) such that you are no longer able to recognize family &amp; friends”</td>
<td>3. CPR preference questions with 5-point scale (1: definitely yes; 2: probably yes; 3: uncertain; 4: probably not; 5: no)</td>
<td>-22 % of respondents chose option 1 or 2 for CPR preference if having Alzheimer’s disease; 88% of respondents chose option 2 in current health state</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>60 % married</td>
<td>3. Asking subjects for CPR preferences in 2 scenarios: in their current health state and “if with memory loss and senility (Alzheimer’s) such that you are no longer able to recognize family &amp; friends”</td>
<td>4. Correlation between demographic &amp; knowledge variables and decreased preference for CPR in Alzheimer’s disease scenario</td>
<td>4. Correlation between demographic &amp; knowledge variables and decreased preference for CPR in Alzheimer’s disease scenario</td>
<td>-predictors of refusing CPR in scenarios with Alzheimer’s disease: Alzheimer’s disease knowledge or experience with the disease(p&lt; 0.001); older age (p&lt; 0.001); greater income (p&lt; 0.004); female sex (p&lt; 0.01); nonwhite race (p&lt; 0.04)</td>
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<tr>
<td></td>
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<td>Mean education year: 12.6 ± 3.3</td>
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<td>Household income: 66% ≥ $ 15,000; 24%&lt; $ 15,000</td>
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<td>Residence: 31% rural; 37% small town; 32% suburbs/city (&gt;50000 population)</td>
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<td></td>
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<td>Religion: 76 % protestant; 12 % catholic</td>
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</tbody>
</table>

1. N= total number of respondents. 2. n= no of respondents in individual groups.
Table of evidence (Table 3):

<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence</th>
<th>N=22 patients(1) &amp; Carers(2) characteristics</th>
<th>N=11 Intervention(s)</th>
<th>Comparison (N=11)³</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size ³</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sampson et al. (2011)</td>
<td>RCT (1+)</td>
<td>1. FAST³ scale 7a or above: 30%/74%</td>
<td>Offering an information pack to carer³</td>
<td>1. An information pack was offered to carers³</td>
<td>Baseline, at 6 weeks, 6 months, 3 months after bereavement</td>
<td>Primary outcome:</td>
<td>Primary outcome:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean Age: 85/88 years</td>
<td>Two major Components</td>
<td>1. Assessment of palliative care needs of patients (30 mins): dementia severity, the presence of delirium, communication, pressure sore risk &amp; severity, food &amp; fluid intakes, swallowing &amp; feeding, and pain level</td>
<td>2. Usual care given</td>
<td>1. The number of carers making an ACP</td>
<td>1. 7 carers made ACPs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sex: 90%/77% female</td>
<td>- formulate a management plan &amp; findings are used for the framework in component 2</td>
<td></td>
<td></td>
<td>Secondary outcomes³:</td>
<td>Secondary outcomes:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Major admitting diagnosis:</td>
<td>2. A framework for discussing ACP with carers - up to 4 consultations (&gt;5 days apart).</td>
<td></td>
<td></td>
<td>1. Carer distress (KD10)</td>
<td>1. After 6 months score differences:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>chest infection 30%/27% :UTI10%/22%</td>
<td>1st consultation: assessing knowledge level about dementia, the severity of dementia &amp; prognosis for the patients, patients’ physical needs, the social situation &amp; current social support levels, records of previous preferences for care.</td>
<td></td>
<td></td>
<td>KD10 = -7.7/-6.1</td>
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<tr>
<td></td>
<td></td>
<td>From home; residential; nursing home : 50%/20%; 30%/18%;18%/59%</td>
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<td></td>
<td>EQ-5D= +0.2/+0.1</td>
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<td></td>
<td>Education stopped before age 16: 43%/53%</td>
<td></td>
<td></td>
<td></td>
<td>DCS= -15.4/-10.7</td>
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<tr>
<td></td>
<td></td>
<td>Caucasian: 78%/91%</td>
<td></td>
<td></td>
<td></td>
<td>DSI= -10.2/-3.8</td>
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<tr>
<td></td>
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<td>Admission by emergency service: 78%/100%</td>
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<td>STAXI= -1.9/-1.9</td>
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<td></td>
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<td>Admission length:23/24</td>
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<td></td>
<td>LSQ= +0.9/+0.9</td>
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<td></td>
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<td>Readmissions ≥1: 50%/37%</td>
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<td>VAS (pain)= 0/+0.6</td>
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<td>Mean age:57/60 year; Male:30%/64%</td>
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<td>VAS (distress)= -0.2/-0.5</td>
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<td>Education stopped before age 16: 22%/25%</td>
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<td></td>
<td>2. Post bereavement score differences::</td>
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<td></td>
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<td>Working:80%/50%; Caucasian: 80%/91%</td>
<td></td>
<td></td>
<td></td>
<td>KD10 = -12.7/+2.3</td>
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<tr>
<td></td>
<td></td>
<td>Religion (Christian; Jewish): 40%/41%;40%/32%</td>
<td></td>
<td></td>
<td></td>
<td>EQ-5D= +0.3/-0.1</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>No active caring role: 60%/82%</td>
<td></td>
<td></td>
<td></td>
<td>DCS= Not completed/ -4.1</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Major relationship: 50% (daughter)/ 45% (son)</td>
<td></td>
<td></td>
<td></td>
<td>STAXI= -2.9/+8.7</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>LSQ= +1.4/-1.5</td>
<td></td>
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<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Post bereavement score:</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>SWC-EOLCD= 23/ 27.6</td>
<td></td>
</tr>
</tbody>
</table>

### Table of evidence (Table 4):  

<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence</th>
<th>Patients characteristics (Elderly / Surrogates)</th>
<th>Intervention(s)</th>
<th>Comparison (n= 6)¹</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size (Control group/ Intervention group)</th>
</tr>
</thead>
</table>
| Volandes et al. (2009a) | RCT (1+)                      | Mean age: 83 / 67.5 year                      | The subjects listen to the verbal narrative followed by watching a 2-minute video which describes a patient with advanced dementia:  
1. Narrative describes the disease base on the functional assessment staging stage 7a (threshold for advanced dementia). It states that the disease is an incurable brain illness due to many years of Alzheimer’s disease or a series of stroke with salient features²  
2. The video decision support tool³ (by a portable computer) described the main features of the disease as in the narrative by presenting an 80 year old female patient with advanced dementia together with her 2 daughters in the nursing home setting. She was shown being unable to respond to their attempts at conversation, being pushed in a wheelchair and hand-fed pureed food (showing the salient features³) | Listen to an identical verbal narrative describing advanced dementia as the intervention group | 9 months | 1. The primary outcome measure:  
- Patients’ preferences for care if in a state of advanced dementia categorized as 3 options (life-prolonging, limited or comfort)³.  
- Surrogates predicted patients’ preferences for care chosen based on the substituted judgment criterion.  
- Concordance rate of preferences among patients & surrogates  
2. Secondary Outcome measure:  
- Knowledge scores³ for advanced dementia (both patients and surrogates)  
- Perceived value of the video in intervention group (a 4-point Likert scale) | 1. Goal of care chosen (comfort care; limited care; life-prolonging care):  
50%; 17%; 33% / 100%; 0%; 0%  
2. Number of the surrogates chose correctly what the patients want if in a state of advanced dementia for these patients:  
2/8  
-a concordance rate (33%/100%) (P=0.015 compared with the verbal narrative-alone group)  
3. Knowledge score:  
Patients (0.3± 1.6 versus 2.1± 1.6, P=0.068)  
Surrogates (2.0± 1.3 versus 2.5± 1.4, P=0.50).  
4. 94% dyads in intervention group Rated the video as “very helpful” or “somewhat helpful”; 88% felt “very comfortable” or “somewhat comfortable” viewing the video; and 94% would “definitely” or “probably” recommend the video to others. |

1. n= number of patient and surrogate dyads  
2. Salient features: inability to communicate understandably with others, walk without assistance & feed oneself.  
3. Goals of care: life-prolonging care (CPR, MV), limited care (hospitalization, antibiotics, but not CPR), and comfort care (only treatment to relieve symptoms).  
4. Knowledge scores ranged from 0-5, higher scores indicating greater knowledge.
### Table of evidence (Table 5):

<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence</th>
<th>Patient characteristics (control/ intervention)</th>
<th>Intervention(s) (N= no. of subjects)</th>
<th>Comparison</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size (Control group/ Intervention group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volandes et al. (2009b)</td>
<td>RCT (1+)</td>
<td>Mean age: 75/75 years</td>
<td>(N= 94) The subjects listen to the verbal narrative followed by watching a 2 minute video which describes a patient with advanced dementia: 1. Narrative describes the disease base on the functional assessment staging stage 7a (threshold for advanced dementia). It states that the disease is an incurable brain illness due to many years of Alzheimer’s disease or a series of stroke with salient features² 2. The video decision support tool³ (by a portable computer) described the main features of the disease as in the narrative by presenting an 80 year old female patient with advanced dementia together with her 2 daughters in the nursing home setting. She was shown being unable to respond to their attempts at conversation, being pushed in a wheelchair and fed with pureed food (showing the salient features²)</td>
<td>(N=106) Listen to an identical verbal narrative describing advanced dementia as the intervention group</td>
<td>9 months</td>
<td>1. Preferred goal of care if developing advanced dementia immediately after interventions and after 6 weeks: life prolonging care (CPR; MV)⁴; limited care (admission to hospital, antibiotics but not cardio-pulmonary resuscitation) or comfort care (treatment only to relieve symptoms)</td>
<td>1. Preferred goal of care: 64%/86% (comfort care); 19%/9% (limited care); 14%/4% (life prolonging care); 3%/1% (uncertainty for preferences) (χ²=13.0, df=3, P= 0.003) - greater proportion in intervention group choosing comfort care (22 % difference, 95% CI; 11% to 34%, p&lt;0.001) - Mean knowledge score¹: 3.8 (SD 1.3) / 4.5 (SD1.0), p&lt; 0.001 - Factors increasing to choose comfort care: being a college graduate or higher; good/ better health status; greater health literacy; white race &amp; being randomized to the intervention group (p&lt;0.05) - Intervention subjects were more likely to choose comfort care than control subjects (adjusted odd ratio 3.9, 95% CI, 1.8 to 8.6) 2. Preference change after 6 weeks: 29%/6%; the K statistic for preference stability: 0.35/0.79 (p&lt; 0.001 for difference)</td>
</tr>
</tbody>
</table>

1. It is calculated by adding responses to 5 questions, testing respondent’s knowledge of advanced dementia. Score 0-5, higher scores indicating greater knowledge. 2. Salient features: inability to communicate understandably with others, walk without assistance & feed oneself. 3. Video available on [http://www.acpdecisions.org/](http://www.acpdecisions.org/) 4. CPR: cardiopulmonary resuscitation; MV: mechanical ventilation
Table of evidence (Table 6):

<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence</th>
<th>Patients characteristics</th>
<th>Intervention(s)</th>
<th>Comparison</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volandes et al. (2011)</td>
<td>RCT (1+)</td>
<td>Mean age: 75/73 year</td>
<td>1. The subjects listen to a verbal narrative depicting advanced dementia &amp; goals of care. It was based on Functional Assessment Staging stage 7a (threshold for advanced dementia). It states that the disease is an incurable brain illness due to many years of Alzheimer’s disease or a series of stroke with salient features². 3 levels of medical treatments &amp; corresponding goals³ are stated.</td>
<td>1. Listen to the identical narrative as the intervention group</td>
<td>Recruitment period: 1/12/2008-30/1/2010 Exact length of follow up not mentioned</td>
<td>1. Preferred goal of care in advanced dementia 2. Factors associated with a preference for comfort care (age, gender, race, education, marital status, health status, personal history of dementia, previous relationships with a person with advanced dementia, health literacy and randomization group) 3. Perceived value for the video</td>
<td>1. Preferred goal of care (life-prolonging care; limited care; comfort care): 16%; 12%; 72%/0%; 9%; 91% (χ²=6.3, df=2, p=0.047) 2. Factors increasing chance to prefer comfort care: white race (OR 4.0, 95% CI, 1.1-13.9, p=0.041); female (OR 3.6, 95% CI, 1.1-11.6, P=0.037); randomization to the intervention arm (OR 3.9, 95% CI, 1.0-15.1, P=0.047); greater health literacy (P=0.003) 3. 94% of subjects highly accepted the video decision support tool in the intervention group (95% CI, 80 to 99). 97% of subjects would recommend the video to others (95% CI, 84-100)</td>
</tr>
</tbody>
</table>

1. n= number of subjects. 2. Salient features: inability to communicate understandably with others, walk without assistance & feed oneself. 3. 1st level (life-prolonging care): patients can have all medically treatments including cardiopulmonary resuscitation (CPR) if indicated; the goal is to prolong life at any cost. 2nd level (limited care): patients can have treatments including hospitalization, intravenous fluids, antibiotics, but not CPR & intensive care unit treatments; the goal is to keep physical functions. 3rd level (comfort care): patients can have oxygen & analgesics but not intravenous therapies & hospitalization until need to provide comfort; the goal is to maximize comfort & relieve pain. 4. The video described the main features of the disease as in the narrative by presenting an 80 year old female patient with advanced dementia together with her 2 daughters in the nursing home setting. She was shown being unable to respond to their attempts at conversation, being pushed in a wheelchair and hand-fed with pureed food (showing the salient features²). Then video showed images for the goal of care in advanced dementia (Life- prolonging care images: a ventilated patient being cared by respiratory therapist in an intensive care unit. Physicians demonstrated CPR & intubation with a simulated code, administering different intravenous medications like vasopressors by a venous catheter. Limited medical care images: a patient wore a nasal cannula, another one receiving antibiotics intravenously in a typical medical ward. Comfort care images: a patient with home hospice care receiving pain medications & another one receiving oxygen via a nasal cannula comfortably at home, and another patient performed self-care with a medical attendant’s assistance. An African American clinician described the goals of care. All patients were in white. |
### Table of evidence (Table 7):

<table>
<thead>
<tr>
<th>Bibliographic citation</th>
<th>Study type; Level of Evidence</th>
<th>Patients characteristics (Control group/ Intervention group)</th>
<th>Intervention(s) (n= 50)¹</th>
<th>Comparison (n= 51)¹</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size (Control group/ Intervention group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volandes et al. (2012)</td>
<td>RCT (1+)</td>
<td>Mean age: 76/ 79 year</td>
<td>The subjects viewed a 6-minute Goals-of-Care Video² (by a portable computer) describing 3 goals of care.</td>
<td>Listen to an verbal narrative describing potential goals of care (life-prolonging care, limited medical care and comfort care), each goal has its own aim³</td>
<td>Recruitment July 1, 2010 - February 28, 2011.</td>
<td>1. The primary outcome measure: preferences for comfort versus other options&lt;br&gt;2. Secondary outcome measure: Concordance of preferences with documentation in the medical record</td>
<td>1. Preferences of care (Comfort; limited; life-prolonging; uncertain): 57%; 8%; 33%; 2% / 80%; 8%; 12%; 0%&lt;br&gt;2. Randomized to the video group was associated with greater chance of opting for comfort (unadjusted rate ratio, 1.4; 95% CI, 1.1–1.9, p = 0.02)&lt;br&gt;3. 29% of subjects in control group had a do-not-resuscitate (DNR) order (k statistic 0.18; 95% CI–0.02 to 0.37); 33% of subjects in the intervention group chose comfort had a DNR order (k statistic 0.06; 95% CI–0.09 to 0.22).</td>
</tr>
</tbody>
</table>

1. \( n= \) number of patients<br>2. Visual images in the video- life-prolonging care images: a ventilated patient being attended by respiratory therapists in an intensive care unit; clinicians conducting cardiopulmonary resuscitation and intubation with a simulated code on a mannequin and administering vasopressors via a venous catheter; limited medical care images : a patient getting antibiotics through a peripheral intravenous catheter in a typical medical ward service, and a patient wearing nasal cannula for oxygen therapy; comfort care images: pain medications were being received by a patient on home hospice care; a patient wearing a nasal cannula for oxygen at home, and a patient was being assisted by a medical attendant for self-care.<br>3. Aims of 3 goals of care: life-prolonging care- to prolong life using all available medical care, and includes cardiopulmonary resuscitation and treatments in the intensive care unit; limited medical care- to maintain physical and mental functioning, including treatments such as hospitalization, intravenous fluids, antibiotics, but excludes cardiopulmonary resuscitation and treatments in the intensive care unit; comfort care - to maximize comfort and to relieve pain, including oxygen and analgesics, but excludes intravenous therapies and hospitalization until need to provide comfort.
Appendix 10

Levels of evidence (SIGN grading system 1999 – 2012)

1++ High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias

1+ Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias

1- Meta-analyses, systematic reviews, or RCTs with a high risk of bias

2++ High quality systematic reviews of case control or cohort or studies

High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal

2+ Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal

2- Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal

3 Non-analytic studies, e.g. case reports, case series

4 Expert opinion
Grades of recommendations (SIGN grading system 1999 – 2012)

**Grade A**

At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or

A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results

**Grade B**

A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or

Extrapolated evidence from studies rated as 1++ or 1+

**Grade C**

A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or

Extrapolated evidence from studies rated as 2++

**Grade D**

Evidence level 3 or 4; or

Extrapolated evidence from studies rated as 2+
## Critical Appraisal Checklist (SIGN)

### SIGN METHODOLOGY CHECKLIST FOR CONTROLLED TRIALS

<table>
<thead>
<tr>
<th>Section 1: Internal validity</th>
<th>Ahronheim et al.,2000</th>
<th>Griffith III et al.,1995</th>
<th>Sampson et al.,2011</th>
<th>Volandes et al.,2009a</th>
<th>Volandes et al.,2009b</th>
<th>Volandes et al.,2011</th>
<th>Volandes et al.,2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 The study addresses an appropriate and clearly focused question.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1.2 The assignment of subjects to treatment groups is randomised.</td>
<td>Can’t say</td>
<td>Yes-random digit-dialing</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1.3 An adequate concealment method is used.</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1.4 Subjects (S) and investigators (I) are kept ‘blind’ about treatment allocation.</td>
<td>Yes(I); Can’t say(S)</td>
<td>Yes</td>
<td>No(I); Can’t say(S)</td>
<td>No(I); Can’t say(S)</td>
<td>No(I); Can’t say(S)</td>
<td>No(I); Can’t say(S)</td>
<td>No(I); Can’t say(S)</td>
</tr>
<tr>
<td>1.5 The treatment and control groups are similar at the start of the trial.</td>
<td>Yes</td>
<td>Can’t say</td>
<td>No</td>
<td>Can’t say</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1.6 The only difference between groups is the treatment under investigation.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1.7 All relevant outcomes are measured in a standard, valid and reliable way.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1.8 What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed?</td>
<td>Total 1% drop out (but which group not mentioned)</td>
<td>Total 58.2% (but which group not mentioned)</td>
<td>Control-63.6%; Intervention -68.2%</td>
<td>0%</td>
<td>11% drop out for each group</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>1.9 All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis).</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Not applicable</td>
</tr>
<tr>
<td>1.10 Where the study is carried out at more than one site, results are comparable for all sites.</td>
<td>NA</td>
<td>NA</td>
<td>Can’t say</td>
<td>Can’t say</td>
<td>Can’t say</td>
<td>NA</td>
<td>Can’t say</td>
</tr>
</tbody>
</table>

### Section 2: OVERALL ASSESSMENT OF THE STUDY

<table>
<thead>
<tr>
<th>2.1 How well was the study done to minimise bias? Code as follows: High quality (++); Acceptable (+); Low quality (0)</th>
<th>+</th>
<th>+</th>
<th>++</th>
<th>+</th>
<th>+</th>
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<tr>
<td>2.2 Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>2.3 Are the results of this study directly applicable to the patient group targeted by this guideline?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

| Level of Evidence | 1+ | 1+ | 1+ | 1+ | 1+ | 1+ | 1+ | 1+ |
Narrative Describing Advanced Dementia (Volandes et al., 2009a; Volandes et al., 2011)

I am going to describe to you an illness called advanced dementia, like advanced Alzheimer’s dementia, that you may or may not be familiar with. Advanced dementia is an incurable disease of the brain in which one is not able to communicate with others. People in advanced dementia are not able to move around or walk, get out of bed independently, eat by oneself, or communicate understandably with others. People with advanced dementia often have difficulty chewing or swallowing, and require assistance with feeding oneself. Advanced dementia is an incurable disease and most commonly occurs after many years of Alzheimer’s disease or as the result of strokes. People are not able to answer any questions or tell you about themselves.

Narrative Describing the Goals of Care

I am going to ask you a question about your preferences for medical care if you had a disease called advanced dementia. I will ask you what you prefer. You have three choices for medical care if you had this condition. I will first review these three choices with you. The three choices for medical care that I want you to think about for advanced dementia are life-prolonging care, limited care, and comfort care.

Life-Prolonging Care
The goal of this category of care is to prolong life. There are no limits to care. This choice includes everything a modern hospital has to offer to maintain your life. Such procedures include: cardiopulmonary resuscitation or CPR in which a doctor pushes on your chest when the heart stops and will often use electricity to shock the heart; being placed on a breathing machine, also known as life support, in which a tube is placed down your throat into the lungs; and other medical procedures performed in the intensive care unit or ICU. The goal is to prolong life.

Limited Care
The goal of this category is to maintain physical and mental functions. Care will depend on your physical and mental functioning. Such care includes intravenous (IV) therapies like antibiotics and hospitalization. But does not include cardiopulmonary resuscitation/CPR and intensive care unit/ICU care. The goal is to maintain physical and mental functioning.

Comfort Care
The goal of this category is to maximize comfort. Only measures that comfort or relieve pain are performed. The aim is to relieve pain and to be kept as pain-free as possible. Comfort care does not include cardiopulmonary resuscitation/CPR, respirators, intensive care unit/ICU care, and generally would not include IV therapy or hospitalization. The goal is maximizing comfort and relieving pain. Imagine you have advanced dementia and became very ill and in need of medical treatment. What category of care would you want to have provided: Life-Prolonging Care, Limited Care, or Comfort Care?

Remarks: Sentences that are underlined & in bold form come from Volandes’s study (2011) only.
Appendix 14

The content of video decision aid (Volandes et al., 2011)

The video presents an 80-year-old female patient with advanced dementia together with her two daughters in the nursing home setting. The patient fails to respond to their attempts at conversation (inability to communicate). The patient is next shown being pushed in a wheelchair (inability to ambulate). Lastly, the patient is hand-fed pureed food (inability to feed oneself). Video images then followed of the goals of care in advanced dementia. Life-prolonging care images included: an intensive care unit with a ventilated patient being tended to by respiratory therapists; a simulated code with clinicians illustrating cardiopulmonary resuscitation (CPR) and intubation; and various intravenous medications including vasopressors administered through a venous catheter. Visual images to depict limited medical care included: a patient getting antibiotics via a peripheral intravenous catheter; scenes from a typical medical ward service; and a patient wearing a nasal cannula. The video depiction of comfort care included: a patient on home hospice care receiving pain medications; a patient with a nasal cannula comfortable on oxygen at home; and, a medical attendant assisting a patient with self-care. The goals-of-care segment of the video is narrated by an African American physician. All the patients depicted in the video are white.
**Appendix 15**

**Time table for the study: 16 months**

<table>
<thead>
<tr>
<th>Months</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>16</th>
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<tbody>
<tr>
<td>Phases</td>
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<td>The preparatory phase - proposed ACP intervention planning, briefing session¹, materials preparation², staff training³ and pilot⁴ of the proposed ACP intervention</td>
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<td>The implementation of ACP⁵</td>
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<tr>
<td>Data collection (patient outcomes)</td>
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<tr>
<td>Data collection (healthcare provider and system outcomes)</td>
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<tr>
<td>Evaluation</td>
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</table>

Remarks:

1. Briefing session lasts 30 minutes with the service manager, general manager, nurses, training and promotion manager, geriatrician of the MC as the target audience.
2. The materials to be prepared include the information pack about advanced dementia, ACP and palliative care definition; forms for the Advance Directive and its revocation; the ACP decision aiding video.
3. Training session that lasts for three hour with the nurses as the target audience.
4. After first month of the preparatory phase, the pilot of which involves 18 clients potentially will take place and last a month. The evaluation of the pilot result will be feedback to fine tune the protocol.
5. The length of intervention will take a year as suggested by the majority of reviewed studies (6 out of 7).
### Table for material cost of the proposed ACP intervention

<table>
<thead>
<tr>
<th>Materials</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. One hard copy of an information pack about advanced dementia, ACP and</td>
<td>$ 0.5 x 3 = $1.5</td>
</tr>
<tr>
<td>palliative care definition (each contains 3 pages)</td>
<td></td>
</tr>
<tr>
<td>2. The Advance Directive form (each contains 6 pages)</td>
<td>$ 0.5 x 6 = $3.0</td>
</tr>
<tr>
<td>3. Revocation of Advance Directive form (each contains 2 pages)</td>
<td>$ 0.5 x 2 = $1.0</td>
</tr>
<tr>
<td>4. An Oral Revocation of an Advance Directive (each contains 2 pages)</td>
<td>$ 0.5 x 2 = $1.0</td>
</tr>
<tr>
<td>5. Video production cost</td>
<td>$20000</td>
</tr>
<tr>
<td>6. Total material cost for potential 18 clients in pilot (1 month)</td>
<td>($ 6.5 x 18) + $20000</td>
</tr>
<tr>
<td></td>
<td>= $117 + $20000</td>
</tr>
<tr>
<td></td>
<td>= $20117</td>
</tr>
<tr>
<td>7. Total material cost for pilot and potential 159 clients in long term</td>
<td>($ 6.5 x 159) + $20000</td>
</tr>
<tr>
<td>(1 year)</td>
<td>= $1033.5 + $20000</td>
</tr>
<tr>
<td></td>
<td>= $21033.5</td>
</tr>
</tbody>
</table>
Flow chart of ACP intervention in MC

1. PWD visits the MC
2. Screening for the eligibility (PWDs with mild to moderate stage of dementia) by cognitive assessment like MMSE
3. Deliver an information package to PWD and PWD's surrogate in the waiting room
4. Obtain verbal consent for willingness to ACP intervention
5. Proceed to broadcast the ACP aiding video to the dyad in a quiet room locating in the clinical area if verbal consent gained
6. Nurse provide ACP consultations with the dyad (maximal 4 weekly sessions)
7. Proceed to an ACP discussion and document an AD during a medical consultation if the dyad verbally agrees
Reference


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Doi: 10.1111/j.1365-2702.2010.03353.x


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Doi:10.1136/bmj.b2159
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DOI: 10.1089/jpm.2010.0299

Volandes, A.E., Brandeis, G.H., Davis, A.D., Paasche-Orlow, M.K., Gillick, M.R., Chang, Y.,


goals-of-care video for elderly patients admitted to skilled nursing facilities.


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Doi: 10.1002/gps.4092

Doi:10.1155/2012/406852