Exploring the Feasibility of Advance Care Planning in Persons with Early Cognitive Impairment

Kenny Cheong1, Paul Fisher1 2, Jenny Goh3, Lynette Ng3, Hui Mien Koh4, Philip Yap4

1James Cook University, Singapore

2Department of Clinical Psychology, Norwich Medical School, University of East Anglia, UK

3Department of Medical Social Service, Khoo Teck Puat Hospital, Singapore

4Department of Geriatric Medicine, Khoo Teck Puat Hospital, Singapore

**Correspondence to**

Dr Philip Yap, Senior Consultant,

Department of Geriatric Medicine, Khoo Teck Puat Hospital, Singapore.

90 Yishun Central, Singapore 768828.

yap.philip.lk@alexandrahealth.com.sg

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**ABSTRACT**

**Background/Aim**: Persons with early cognitive impairment (ECI), comprising mild cognitive impairment and early dementia face the risk of diminished mental capacity with progressive disease. Advance Care Planning (ACP) is advocated as a means to uphold the autonomy of individuals and enable them to express their wishes for the future while they still possess mental capacity. This study aims to explore the feasibility of ACP in patients with ECI in Singapore.

**Method**: Consecutive patients undergoing a counseling service for persons with ECI who fulfilled inclusion criteria (Mini Mental State Examination score ≥18, Global Clinical Dementia Rating (GCDR) = 0.5 or 1 were recruited. Demographic and clinical data was collected and the detailed documentation in the case records of the counseling sessions was subjected to a thematic analysis. Differences between patients who were willing to engage in ACP and those who declined were also analyzed.

**Results**: Ninety-three patients (mean age 76.0, 60.2% female) were recruited of which 38.7% chose to engage further in ACP discussions. GCDR was the only factor that emerged significant on bivariate analysis for willingness to engage in ACP (t (79) = 2.191, p< .05, two-tailed). Among those who declined ACP, three main themes emerged from the thematic analysis. The majority showed passivity in discussing ACP and perceived ACP as irrelevant or unnecessary. Patients also displayed avoidance and denial behaviors during ACP discussions.

**Conclusion**: A large proportion of patients with ECI are not open to ACP discussions and the reasons are influenced by personal values, coping behaviours and socio-cultural norms. These findings have important implications for practice.

**INTRODUCTION**

Advance Care Planning (ACP) is a process that aims to inform and facilitate medical decision-making to reflect patients’ values and preferences in the event that they cannot communicate their wishes[[1]](#endnote-1). For patients with early cognitive impairment (ECI), which includes persons with mild cognitive impairment (MCI) and early-stage dementia who are susceptible to losing decisional capacity and ability to make healthcare choices, ACP can be beneficial to enable timely decisions about their future. Research suggests positive outcomes for patients with ECI engaging in ACP, including positive effects on quality of life[[2]](#endnote-2), maintaining independence for as long as possible[[3]](#endnote-3), achieving patient centered care and maintaining patient autonomy[[4]](#endnote-4). However, a recent review paper found limited literature and evidence regarding the best way to approach ACP for people with dementia[[5]](#endnote-5).

Much remains to be understood about the reasons behind the paradox whereby ACP is arguably beneficial yet underused[[6]](#endnote-6) [[7]](#endnote-7). Before attempting to understand the reasons for declining ACP, it is valuable to comprehend the factors leading to ACP completion. To our knowledge, only two studies have explored the reasons people with dementia give for completing ACP4 [[8]](#endnote-8) and they include: patients’ failing health, encouragement from others, illness or death of others, active planning which was associated with financial and healthcare arrangements, and reactive planning which involved patients reacting to an event associated with medical, living situation or financial issue4 8. One study examined prevalence rates and socio-demographic correlates of ACP completion among patients with cognitive impairment[[9]](#endnote-9). The authors found no significant differences in the prevalence of ACP engagement among those with MCI or early Alzheimer’s Disease (AD) compared to those with moderate to severe AD and cognitively intact controls. Across all groups, engagement with ACP was associated with increased age, higher education and having a white American ethnicity9.

To date, only two studies have investigated why patients with dementia do not engage in ACP4 8. The reasons elicited include avoidance, being reluctant to discuss ACP, preferring to leave the decision to others, and not seeing ACP as important or necessary4 8.

In Singapore, awareness and use of ACP has been low although its existence in the more limited form of Advanced Medical Directives dates back to 1996[[10]](#endnote-10) [[11]](#endnote-11). Singaporeans who felt ACP was necessary gave reasons such as “to lessen the financial burden and emotional burden on loved ones”, “to avoid prolonging suffering”, “respects autonomy and guides patients and family”11 [[12]](#endnote-12). Conversely, those who thought ACP was irrelevant remarked: “it was bad luck to talk about death and a cultural taboo”, “they were unlikely to be in a situation that required one” and “they were fearful of destroying patient’s hope”. Given the move to implement a national ACP programme in the country[[13]](#endnote-13), it is timely to conduct studies to better understand the perspectives of the lay public, particularly for patients whom ACP is deemed important given the diagnosis of a progressive and incurable neurodegenerative condition.

Therefore, the goal of this study is to explore, in depth, the perspectives of patients with ECI on ACP in the Singapore context.

**METHOD**

**Participants and procedure**

Ethics approval for the study was obtained from the Domain-Specific Review Board of the National Healthcare Group, Singapore and James Cook University Ethics Committee. The participants comprised consecutive patients diagnosed with MCI or early dementia attending the ECI psycho-education programme of a tertiary hospital memory clinic between 4 October 2012 and 4 June 2013. Patients with ECI fulfilled the following criteria: Mini-Mental State Examination (MMSE)[[14]](#endnote-14) of ≥ 18 or Global Clinical Dementia Rating (GCDR)[[15]](#endnote-15) of 0.5 to 1.0 and having at least ‘fair’ to ‘good’ insight based on the Guidelines for the Rating of Awareness Deficits (GRAD)[[16]](#endnote-16).

During the ECI psycho-education session lasting typically 30 to 45 minutes, patients were introduced to the concept of ACP by a Medical Social Worker (MSW) with formal training and certification in ACP by Respecting Choices©[[17]](#endnote-17), an internationally recognised and evidence-based ACP **programme.** Patients were asked if they would like to engage in further ACP discussions and their decisions and the accompanying reasons were documented in prose in the case records by the MSW. These records provided the content for the qualitative analysis. Socio-demographic characteristics such as age, years of education, gender, marital status, ethnicity, and religion, and clinical measures were also collected.

**MEASURES**

**Mini Mental State Examination**

The MMSE14 is a brief 30-point test commonly used for cognitive assessment and has been validated in Singapore. It can typically be completed in 15 minutes and assesses several cognitive domains including arithmetic, memory and orientation. Its inter-rater test reliability (.88) and test-retest reliability (.98) are high.

**Global Clinical Dementia Rating**

The CDR scale15 assesses global dementia severity based on combined ratings of cognitive, social, and functional aspects of the patient by a clinician. A global score is obtained, ranging from 0 to 3 (0 = normal, 0.5 = questionable dementia, 1 = mild, 2 = moderate, 3 = severe dementia).

**Guidelines for the Rating of Awareness Deficits**

 The GRAD scale16 [[18]](#endnote-18) is completed using a semi-structured interview that assesses the patient’s degree of awareness by comparing the patient’s and caregiver’s information about the patient’s history. Impaired awareness is defined as the absence of knowledge or recognition of cognitive deficits and its impact. It is rated on a four-point scale, ranging from 4 (intact), 3 (mildly disturbed), 2 (moderately disturbed) to 1 (absent). This test has good inter-rater (.73) and test-retest reliability (.73)[[19]](#endnote-19).

**Willingness to engage Advanced Care Planning**

Willingness to engage in further ACP discussions was measured using a dichotomous variable coded “No” and “Yes”.

**DATA ANALYSIS**

**Bivariate Analysis**

 Using the statistical software SPSS Version 16.0 (SPSS Inc., Chicago IL, USA), Chi-square and independent samples t-tests were employed to detect differences in socio-demographic and clinical measures (MMSE, GCDR and GRAD) between patients who were willing or unwilling to engage in further ACP discussions.

**Qualitative Analysis**

The clinical records of the discussion with the MSW were qualitatively analyzed using a thematic analysis approach, closely following the approach of Braun & Clarke[[20]](#endnote-20). The data for the analysis was managed using NVivo 9.0 software (QSR International, Victoria, Australia). For the analysis, all data extracts pertaining to the research question were given one or more codes to identify pertinent sections. Validity and replicability of the coding process was also established[[21]](#endnote-21).

During analysis, groups of codes with similar meanings were placed together to form overarching sub themes20. Less relevant codes were discarded over time. Subthemes with similar information were clustered together leading to the development of wider main themes. Themes and subthemes were checked against every code to ensure relevance. Consensus was reached regarding minor adjustments to the categorization of data and after the themes were confirmed, key quotes were identified to represent the themes. Upon completion of the thematic analysis, the percentage of participants who contributed to a particular theme was tabulated to demonstrate the validity of the theme.

**RESULTS**

**Participant Characteristics**

Mean age of the patients (*n* = 93) was 76 years old, ranging from 58 to 92. Majority were Chinese (90.3%), female (60.2%) and married (58.1%). Buddhists (31.1%), Christians (25.6%) and Taoists (21.1%) comprised the majority and mean MMSE score was 21.31 ± 3.30. Table 1 summarizes the patients’ characteristics.

Only GCDR scores differed significantly between patients who chose to engage in further ACP discussions (*M* = .66, *SD* = .27) and those who declined (*M* = .81, *SD* = .32; t (79) = 2.19, p < .05, two-tailed). The magnitude of the difference (mean difference = .15, 95% CI: .01 to .29) was moderate (eta squared = .06).

**Table 1** Differences in patient variables between those willing to engage in ACP and those not willing

**Variable Willing to Not willing to p value 95% C.I.**

 **engage in ACP engage in ACP**

Mean Age 76.32 75.58 .63 -2.30–3.76

Education Years 7.12 6.20 .43 -3.24–1.40

MMSE Score 22.00 20.88 .11 -2.51– .26

GRAD Score 3.36 3.15 .25 - .55 – .14

GCDR Score .66 .81 **.03** .014 – .29

Gender .43 ---

 Female 24 32

 Male 12 25

Diagnosis Type 1.00 ---

 MCI 9 16

 Dementia 23 41

Marital Status .80 ---

 Single 14 25

 Married 22 32

Ethnicity .99 ---

 Chinese 32 52

 Non-Chinese 4 5

Religion .27 ---

 Oriental Religion 16 31

 Christianity 10 20

 Free-thinker 5 2

 Other Religion 2 4

*Note:* Abbreviations: ACP, Advanced Care Planning; C.I., Confidence Interval; MMSE, Mini-Mental State Examination; GRAD, Guidelines for the Rating of Awareness Deficits; GCDR, Global Clinical Dementia Rating.

Significant values are bolded.

For Diagnosis Type, data were available for 89 participants (96%). Dementia group consists of patients with Alzheimer’s Disease, Vascular Dementia and Mixed Dementia.

For Marital Status, Single consists of patients who are single, widowed and divorced.

For Ethnicity, Non-Chinese consists of patients who are Malays, Indians, Eurasians and other ethnicity.

For Religion, data were available only for 90 participants (98%). Oriental Religion consists of patients who are Buddhists and Taoists. Christianity consists Christians and Catholics. Other Religion consists Muslims and Hindus.

**Willingness to engage in Advanced Care Planning**

 Thirty-six (38.7%) patients agreed to further ACP discussions and the reasons for doing so fell within the categories of welfare, finance and family. Thirty-two (88.9%) wanted to engage in ACP to plan for their property and assets, 15 (41.7%) cited planning for personal welfare as a reason, which included medical and social care, and 13 (36.1%) wanted ACP for their family.

Fifty-seven (61.3%) patients declined further ACP discussions and qualitative analysis revealed three main themes. These themes and their accompanying subthemes are detailed in Table 2 and described below.

**Table 2** Themes and Subthemes

**Passive acceptance** **ACP irrelevant and unnecessary** **Avoidance and Denial**

Leave future to family Planning “done” Avoidance

Leave future to Providence/Destiny Lack of finances Uncertainty/Insecurity

Leave future to others Lack of support Denial

*Note:* Main themes are bolded.

Theme 1: Passive acceptance

 This comprised 3 subthemes: leave future to family, leave future to others and leave future to providence and destiny. This theme highlights the choice of passivity and inaction even though the option of planning for the future through ACP was presented. Patients expressed they felt secure in having adequate resources to depend on and were resigned to whatever the future held for them, be it favorable or unfavorable. This theme was present in the accounts of 91.2% of those who declined ACP.

The majority of those were comfortable to leave the future to their family, particularly their children, assumed they would do what was appropriate. Notably, most of these patients were living with and financially dependent on their children. For example, the MSW reported that patient 46 was:

*…aware that his memory is deteriorating and will eventually lose mental capacity, [but] he does not see the need to make advance plans for himself…has faith and trust in his children and believes they will make good healthcare and welfare decisions for him*.

Some patients were prepared to accept any future arrangements made for them. As regards to future care arrangements, participant 24 expressed that “*if children choose to place him in a nursing home, he will have no say*”. Patients who were single, without close relatives displayed little concerned in having to depend on more distant relations. For instance, of patient 56, the MSW wrote:

*If she cannot walk well, she plans to rest in bed more at home and wait for niece’s family to buy meals for her. She leaves long-term planning to her niece’s family as she does not have the resources to plan for herself and trusts them to make plans for her*.

Patients were also willing to leave the future to providence and destiny. Patient 80 stated that she would “*leave everything to God and cope through her strong faith and daily prayers*”. Similarly, patient 59 reported that he will“*leave decisions to his son, fate and destiny*”.

Theme 2: ACP perceived as irrelevant or unnecessary

 The second theme comprised 3 subthemes: planning “done”, lack of finances and lack of support. Under this theme, despite acknowledging the theoretical importance of planning for the future, patients did not see the need to do so. Furthermore, some failed to understand the relevance of ACP and its immediacy. Forty-five patients (78.9%) gave reasons for declining ACP pertaining to this theme.

About half of them felt that completing ACP was unnecessary as they had ‘completed’ their planning or engaged in informal planning, which usually consisted of verbally informing close ones about end-of-life decisions. Many had initiated financial planning by creating joint savings accounts or completing a will. Patient 83 told the MSW that “*she has a joint savings account with one of her sons and done up a will to bequeath the flat to her children…no one can touch the house when she is alive”.* Given this, she resisted formal ACP*.*

Another aspect of ACP irrelevance pertained to the lack of finances. These patients reported they had no assets, were financially dependent on their family or had little savings. Patient 53 expressed that “*it is important to complete ACP but thinks he does not have much assets to worry*”, while patient 51 remarked that “*she has little property and finances, so no immediate need [for ACP]*”.

The third subtheme revolved around lack of support. Some patients were not keen to discuss ACP due to a lack of trust in their family. For example, patient 54 reported he was “*not keen to consider ACP as he has reservations and lack of trust over wife and children’s abilities to follow his wishes*”. Family members may also influence non-engagement in ACP discussions in two other ways: 1) agreeing with the patient ACP is irrelevant and 2) dismissing patients’ end-of-life plans. Pertaining to the former, the son of patient 7 explained that the “*family is supportive and understands patient’s wishes, thus agreeing that ACP is not necessary*”. As regards the latter, patient 42 shared her plans were dismissed by her children after “*informing her daughters about splitting her savings and having a sea-burial”*.

Theme 3: Avoidance and Denial

The third theme comprised three subthemes: avoidance, uncertainty and insecurity, and denial. This theme highlights coping strategies and defense mechanisms initiated by patients when being broached with the topic of planning for end of life. The accounts of 40 patients (70.2%) who declined ACP discussions showed facets of either avoidance or denial. Avoidance was demonstrated in both active and passive ways. For instance, when discussing future plans about finances, patient 14 “*became rather evasive…showing signs of discomfort*”, whereas participant 43 “*got impatient and asked to leave session to go to the toilet*”. Those who showed passive avoidance were contented to “*live by the day*” (patient 32) or “*face it when the situation arises*” (patient 88), even when they were told they might eventually lose the ability to make decisions for themselves with progressive dementia.

 The apparent uncertainty and insecurity about the implications of ACP also contributed to avoidance coping. Patient 3 shared that “*she is wary about doing [advance directive] as she is worried that it will cause conflict between her two sons*”, whereas patient 75 expressed “*she does not want her children to be unhappy that she is ‘playing favorites’ by appointing certain children as ‘donee’”.*

 Finally, the strong levels of denial in some patients precluded deeper conversations about ACP. Patient 11 remarked, “*he believes strongly that his forgetfulness is solely due to his inactive lifestyle which can be easily ‘reversed’ once he has better access to a [conducive] environment and resumes [past] activities*”. Apart from misconstruing that dementia can be overcome, some perceived themselves as still healthy with claims of being “*currently far away from [dementia condition] and still very clear-minded*” (patient 73).

**DISCUSSION**

To our knowledge, this is the first study investigating reasons for declining ACP discussions among patients with ECI by employing a qualitative methodology. It is striking that the results suggest the overall willingness to engage in further ACP conversations is modest at 38.7%. The findings are consistent with a previous local study10 which found that opinions towards ACP have remained largely negative and static throughout the years.

 The only significant difference found between patients who declined or accepted ACP was dementia severity by GCDR scores. This is in contrast to previous research that found age, education level, and ethnicity, and not cognitive function to be significantly associated with completion of ACP in individuals with ECI9. However, the current study investigated interest in further ACP discussions whereas previous research examined actual completion rates. GCDR scores for patients who declined ACP were higher, implying more advanced cognitive impairment than those who accepted with a moderate effect size in the difference. Earlier studies posit there is a point at which cognition decreases so critically that ACP can no longer be meaningfully undertaken5. Our findings add to the evidence that it is pertinent to engage patients with cognitive deficits as early as possible for successful engagement in ACP.

The reasons for wanting to pursue ACP among our patients with ECI were consistent with those in extant literature4 11 12; personal welfare, family and financial matters were the main considerations. Planning for finances was foremost and comparable in importance to a previous Singapore study11, however, planning in advance for family and personal welfare was relatively less considered in our study. The earlier study11 involved a younger sample with presumably better education and knowledge, factors that are generally associated with higher uptake of ACP. Younger subjects are also more likely to have young families, which underscores the importance of planning for one’s family and welfare. Nonetheless, even in our older cohort of patients with ECI, our findings emphasize the need to educate the public that ACP goes beyond financial arrangements and entails planning for healthcare and other end-of-life matters.

A high proportion of patients who declined ACP adopted a passive and apathetic stance, similar to findings in previous studies4 8, and the predominantly Chinese patients in our study could in part explain the findings. In East Asian culture, Confucianism and the high importance placed on an individual’s relations with family and society have critical influence on end-of-life decisions12. Within the traditional Asian context, patients may choose to leave decision-making to their children. Interestingly, although leaving the future to God was elicited as a subtheme, religion was not found to be significantly associated with willingness to engage in ACP discussions. Further research is thus necessary to examine the effects of religion on ACP completion especially in the Asian context.

A significant proportion of the patients deemed ACP irrelevant or unnecessary as they had undertaken informal planning in the form of writing a will or creating joint bank accounts with particular family members. As such, these patients perceived planning to have been ‘completed’. This highlights the lack of knowledge about ACP in our patients10 11 and plausibly in the general public as well whereby the difference between formulating a will and ACP appears unclear. More systematized effort to explain the purpose of living wills and appointing healthcare proxies is certainly needed.

The subtheme, lack of support, has been reported by Schickedanz et al[[22]](#endnote-22); however, in this study the reasons appear more complex. Despite the presence of their families, some patients still struggle to make a decision on whom to depend on or may lack someone they can entrust the future to. Furthermore, family members are not always supportive of engagement in ACP or may adopt a dismissive attitude to patients’ end-of-life decisions. Speaking about death and dying has traditionally been associated with bad luck and is a cultural taboo among Chinese11 12. This uniquely Asian phenomenon can present obstacles to ACP and thus deserves further research to explore ways to overcome the socio-cultural barrier.

Consistent with previous research4 8, many patients appeared unable to contemplate end-of-life issues and avoided discussions around the subject. This could indicate their inability or unwillingness to admit to the dementia diagnosis or the prospect of losing mental capacity, and tended to build a defensive reaction to the topic. Conversely, some patients who did not refrain from ACP discussions expressed uncertainty and anxiety as they were concerned about the consequences of formulating advance directives. This perspective has been cited as one of the limitations of ACP[[23]](#endnote-23) [[24]](#endnote-24)and might suggest that patients are either concerned with causing disagreements among family members or doubt ACP’s effectiveness in conveying their wishes even after formulation of advance directives.

Taken together, the results show patients have varying levels of readiness for ACP, and many encounter difficulties at the pre-contemplation and contemplation steps22. As these difficulties are often experienced at the early stages of the ACP process, intervention by way of education and counseling to empower patients with more knowledge and alleviate their concerns can help. ACP conversations should be initiated early in the continuum of cognitive decline as suggested by the finding of milder cognitive impairment (GCDR) being associated with higher ACP acceptance. Importantly, the implications go beyond patients with cognitive impairment and may be pertinent for all patients in general as many of the factors unveiled pertain to personal values, coping behaviors and socio-cultural norms, over and above barriers imposed by cognitive impairment alone.

Understanding these obstacles is crucial for policymakers, healthcare providers and researchers in designing step-specific interventions to help patients overcome the barriers, engage better in ACP and move towards completing advance care directives22.

 A few limitations of this study are noteworthy. Firstly, the findings may not be readily applicable to other populations as our sample comprised mostly Chinese from a tertiary hospital in a specific location in Singapore. Secondly, the use of MSW’s reports for qualitative analysis instead of verbatim interview transcripts of actual patient encounters can limit the ability to adequately capture the complexities and nuances of patients’ perspectives on ACP. It may also contain the MSW’s personal interpretation and consequently predispose to reporting bias. However, the counseling sessions were conducted by only 2 MSWs with a collective experience of 15 years in the field. Efforts had also been made to ensure consistency in reporting which emphasized careful reporting of the patients’ responses in prose form.

 Finally, the study only captures the patient’s willingness to engage in ACP discussions at a single time point and does not preclude the possibility that some who decline may still change their minds at a later stage. As individuals’ values and beliefs are fluid and may change over time[[25]](#endnote-25), the initial ACP discussion could be the start of a series of conversations which may eventually lead to successful completion of advance care plans. As ACP is an ongoing and dynamic process1, it would be instructive to conduct longitudinal follow up studies to see how many patients will eventually formulate advance care plans.

**CONCLUSION**

 This study shows a significant proportion of patients with ECI are unwilling to engage in ACP discussions and the reasons for declining are more complex than previous research has suggested. With the use of qualitative methods, new themes and rationales that reflect personal values, coping behaviors and socio-cultural norms have emerged, and these findings can be relevant for those without cognitive impairment as well. Discussions on ACP should be initiated as early as possible and it is hoped that a deeper understanding of patients’ perspectives on ACP can guide interventions to help patients overcome the barriers and improve advance directives completion rates.

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