Communications for Advance Care Planning in Dementia (ACP-D)

Lo, Yolanda\(^1\), Chong, Alice\(^2\) & Yuen, Rhoda\(^3\)
\(^1\)Aging & Better Care Limited
\(^2\)City University of Hong Kong and \(^3\)Heart to Health Center Company Limited.

Abstract

Objectives: Hong Kong is aging fast. Advance Care Planning in Dementia (ACP-D) carries great operational value to older adults, their families, policy-makers as well as service operators. ACP-D communications is important in order to support and facilitate older adults. However, very few studies are conducted on the specific communication skills required. Method: This article reports on findings from a qualitative study (n=7, 5 female, 3 married, average age=70) carried out during the pilot study of an ACP-D psycho-education intervention. The intervention was assessed by the first author’s reflection as a researcher and participant observer, comments from the third author as ACP-D advisor and participants’ feedbacks through semi-structured individual interviews. Results: Older adults were found fearful about ACP-D. Critical factors for effective ACP-D communications “H.E.A.R.T.” were identified. These included: Hope, Empathetic curiosity, Autonomy, Resources and Timing. Conclusion: Given the high prevalence of dementia, it is crucial for allied healthcare professionals, adult children, potential proxies as well as older adults to learn about ACP-D communications.

Keywords: Advance Care Planning, Communications, Dementia.

1. Background

Advance Care Planning (ACP) is a process of communication among the patient, his or her family, health care providers and other important persons with regards to one’s care preferences they would like to receive at a time when they may no longer be able to make such decisions or their wishes known [46, 62]. Future health decisions will include the older adult’s earlier specified requests or wishes, using earlier statements that had been communicated before their loss of capacity [20]. ACP is recommended for older people, especially those with cognitive impairment in order to reduce inappropriate hospitalization and increase palliative interventions [1, 10, 16, 43, and 52].

Hong Kong’s life expectancy is among the highest in the world [67]. In Hong Kong, one in every 10 elderly adults over the age of 60, there is a risk of cognitive impairment. For people over the age of 85, there will be one in every three people suffering from this disease [69]. The number of people aged 60 or above with dementia is projected to increase by 222% from 103,433 in 2009 to 332,688 in 2039 [69]. Lacking the clear end-of-life progression in the case of dementia which may lead to loss of capacity [55] and without the legal ACP tools, this will make it more difficult for ACP in dementia (ACP-D). Given the lack of ACP policy and public education in Hong Kong, 81% of Chinese elders with chronic disease never heard of DNACPR (Do-Not-Attempt Cardio-pulmonary Resuscitation), and 73% never discussed [63]. All of the above factors considered, ACP-D carries great operational value to people with dementia and their families, policy-makers as well as service operators.

However, there are many barriers in ACP-D. Older people who are not demented avoid talking, thinking and do not plan for dementia [12]. Those who are more aware of their own future care needs are more anxious and depressed and yet, they are not more likely to formally plan [45]. ACP-D barriers include low health literacy of patients, lack of necessary skills & knowledge of ACP-D, lack of privacy in carrying out ACP-D conversations, difficulty in completing the legal documents and patients not sick enough to think about end-of-life issues [48]. Sinclair, Oyebode & Owens (2016)’s consensus views on ACP-D also suggested that general discussion of values as well as coverage of specific points should be included and that professionals need to offer discussion and information on ACP and finally, individualized communication, tailored to the person with dementia’s wishes and needs were recommended [56].
1.1. Who needs to learn ACP-D communication skills

ACP-D actions would include the expression of one’s own wishes as well as starting to communicate with loved ones and professionals regarding goals of care [22]. There are numerous evidence that Advance Directives and health care proxies alone, while not sufficient for ACP, are useful tools [22]. A well-designed educational and reflective process can be very useful for facilitating meaningful communication about the real important issues that the individual values [36].

Evidence shows that professionals’ interactions with patients during ACP communication may be influenced by their own personal attitudes and experiences about death and dying [4]. In addition, there may be “conflicts” between client autonomy and counselor beneficence [7]. ACP must be conducted by a skilled communicator who is competent in understanding the legal and ethical issues involved and also culturally competent in establishing two-way communications while focusing on patient-centered care [2]. ACP facilitator must be humble, respectful, moral, professional as well as courageous in empowering the individuals [2]. Finally, professionals initiating ACP-D discussions should be well trained to answer questions, skillful enough to avoid destroying hope and with sufficient time to talk [3]. An ACP-D facilitator should therefore, be aware of all of the above concerns, be well trained as well as well prepared in order to facilitate ACP-D discussions.

In a study on the level of dementia-related knowledge among undergraduate students (N= 242) in the health and social care professions in Hong Kong, the students could not get more than half of the questions right, their low performance was attributed to almost all aspects of dementia knowledge and their understanding about dementia treatment was particularly inadequate [33].

Bonifas (2011) suggested that social work educators need to ensure that future practitioners are able to effectively employ such skills and knowledge to practice with frail elders, especially those with dementia [6]. The study on higher education in transforming the quality of dementia care from the University of Bradford also reinforced that practitioners and professionals should acquire the knowledge, skills and attitudes in order to confidently demonstrate compassion, empathetic communication, creative problem solving, critical thinking, reflection as well as partnership working (Downs, Capstick, Baldwin, Surr, & Bruce., 2009).

2. Method

This article reports on findings from a qualitative study carried out during the pilot study of an ACP-D psycho-education intervention, designed to educate the older adults as well as to measure their readiness for ACP-D. The ACP-D psycho-education intervention consisted of three workshops, each consisted of ninety minutes and one hourly session of individual interview. The first workshop was on scope of ACP-D, consisted of education on dementia, risk factors, trajectory, three care levels of care options including life-prolonging, limited care, comfort care and finally, the benefits of ACP-D including autonomy and releasing the burden of loved ones. The second workshop was on ACP-D communications, consisted of education covering the Hong Kong context, without the legislation of Advance Directive and Health Proxy. Drawing reference from Deep, Hunter, Murphy, & Volandes., (2010), and Frieh et al., (2012), ACP-D action was explained in five steps which included considering one’s own care option; choosing one care option; identifying at least one health proxy; communicating with health proxy on decided care option and meeting with professionals on details in ACP-D [15, 22]. The format for the third workshop was focus groups and was carried out for the married and the unmarried groups separately and discussion was on the health proxy issue. The last part was a semi-structured in-depth interview and each participant was guided to identify their own difficulty or concerns, especially with respect to the health proxy issue in their ACP-D action. Decisional uncertainty about ACP may need further clarification of patients’ understanding and values [60].

2.1. Sample

Sampling criteria included age, gender and marital status. The first criterion is age: 60 years of age or above. This group has been identified as the estimated number of people aged 60 and above with dementia would increase from 103,433 in 2009 to 332,688 in 2039, an increase of 222% in Hong Kong [69]. The second criterion is on gender: 65% Female & 35% Male. In Hong Kong, women accounts for 52% for age over 60 and gradually increases to over 62% when over 80 [26]. In addition, according to the latest facts and figures report by The Alzheimer’s Association, almost two-thirds of Americans with Alzheimer’s are women. Finally, it is genuinely much more difficult to recruit male subjects for research study. As such, the 65:35 ratio is used. The third criterion is Marital: 50% married & 50% unmarried (defined as widowed, divorced, separated and the never
married). For age over 60, unmarried accounts for 32% only. Among them, widowed/divorced/separated accounts for 28% while the never married accounts for 4% [26]. In order to achieve our specific purpose in understanding the unmarried group which has a much higher risk of dementia, the sampling criteria was set at 50% for both married and unmarried. This is a purposeful skewing in order to for us to better understand the unmarried group as this is the main purpose of this study.

Sample size was 7. Initial invitation was extended to nine but one rejected due to travel and the other one did not want to participate due to fear of the topic and as such, successful rate was 78%. Average age was 70. There were 5 female, 2 male (71% female and meeting our criterion); 3 married with adult children (M1, M2, M3) and 4 unmarried including 2 never married (U1, U2); 1 divorced without children (U3) and 1 widowed with adult children (U4). All of them were university graduates. All except one were retirees. All of them personally knew someone who was demented. All except one (86%) had subjective memory complaints. Chinese Mini-Mental State Exam (CMMSE) was conducted before the intervention and they scored between 26-28 which was classified as Subjective Cognitive Impairment, defined as 4.5 times more likely to develop Mild Cognitive Impairment (MCI) which can be detected by cognitive tests, but do not cause functional decline or dementia within 7 years [51].

2.2. Data management and analysis

A strategic arrangement to eliminate role-conflict was made and we purposely included a voluntary senior clinician in this qualitative study. There were dual purposes: first of all, this would prevent the “dual roles” of the first author as both a clinician and a researcher, which might confuse the participants. As such, an additional clinician plus a carefully designed mechanism which incorporated training, feedback, evaluation as well as room for improvement was in place. The senior clinician conducted both the focus groups and the individual semi-structured, in-depth qualitative interviews. Evidence shows that psychologists are increasingly involved in working with older adults and their families to plan ahead and mediate conflicts related to financial, residential, health care and other long-term planning dilemmas [47]. This additional clinician was an experienced counseling psychologist, who was very much devoted in helping demented patients and families as well as involved in end-of-life care, with no commercial interests and had agreed to act as the additional clinician during this pilot study out of ethical considerations to train a less experienced clinician and to help develop the ACP-D intervention program. My role was a researcher, a silent observer and would share the same experience as the participants in a focus group [9].

My role as a researcher concentrated on pure observation of the natural scene. With myself being the research instrument, I took notes, described, decoded, generated and translated meaning of more or less naturally occurring phenomenon in the natural setting and also contextualizing as well as triangulating interpretive information that was collected. Initial coding and categorization of common themes were performed. Notes between the married and the unmarried groups were compared. At the individual interviews, I observed the natural phenomenon and gathered information until there was “thick” data [23]. The coding, memo-writing, developing and categorizing eventually led to “saturation” [11], and helped shed more light into this study. The reliability and validity of this part of the study lied in the confidence in the process of inquiry itself. Cross-checking meanings of common themes with the senior clinician also contributed to the reliability. In addition, the audit trail with the notes taken by both the senior clinician and myself were saved and could be examined for accuracy of conclusions.

The intervention was assessed by my own reflection as a researcher and participant observer, comments from the ACP-D advisor (volunteer senior clinician) during a series of subsequent data workshops whereby we discussed our emerging ideas, initial coding and derived at common themes and finally, participants’ feedbacks through focus groups and semi-structured individual interviews. All notes from the ACP-D advisor and myself during both the focus groups and the interviews were cross-checked by each other, thoroughly discussed and anonymized. This led to the following main themes on “Individual’s Difficulties and Fears regarding the Health Proxy issue” and the “Common Fears or Worries in ACP-D”.

3. Results

3.1. Difficulties & Fears in Both the Married and the Unmarried Groups

All participants in the married group (n=3) had adult children. They identified their family members as their health proxy but not everyone was comfortable with this natural choice. M1 thought his wife or elder son would know what to do but not his younger son while M3 reviewed each
family member but had no idea whom to appoint as health proxy as no one seemed to understand her care wishes. M2 was the only one who was comfortable with any of his family member to act as health proxy but he still wanted to sign the Enduring Power of Attorney to play safe.

Verbatim for the Married group (M1, M2, M3) were as follows:

(M1): “…health proxy will naturally be my wife…then my eldest son…he’ll know what to do….but definitely not my younger son…”

(M2): “It is easy, I think I can do it…due to the fact that we travel a lot…my wife and I had made our Wills long time ago…we have always told our children what we want and don’t want…we just need to add the Enduring Power of Attorney, just to play safe…”

(M3): “…there is no hope…my husband doesn’t understand my needs and he probably never will…my children have their own burdens…will need to figure out who else to appoint as health proxy…wonder who else is willing to take up this responsibility?…my father who was demented then had me as a major caregiver before he passed away and I made sure he enjoyed good quality of life…this is my turn now but there is no one who understand my care wishes…this is depressing…”

As for the unmarried group, common themes on fears and worries in ACP-D ran throughout the focus groups and the interviews.

Verbatim for the Unmarried group (U1, U2, U3, U4) were as follows:

(U1): “…the “qualifications” for the health proxy matters a lot…a younger person, must be very trustworthy, my family needs to know him/her well, he/she must be at least financially sound and in a better health condition (than myself, too)…and will need to “educate” him/her on my care wishes…now that I realize the importance of ACP-D, all of the above must take place …I need to catch time for ACP-D…”

(U2): “… I wish I had learnt this ACP-D earlier…my sister-in-law may be a potential one but I don’t think she understand my needs …perhaps I could “advocate” this ACP-D health proxy concept to other church members & get help for each other… I hope I still have time…”

(U3): “…ACP-D is much more complicated than I had anticipated…but I now realize that this is very important and I really need to work on this proxy issue…now that I understand the full responsibility of a proxy…I wonder if this good friend of mine will agree to take up this huge responsibility of honoring my care wishes until the very end…and I am really not sure if she can stand firm (on my behalf ) at the very end…perhaps it would be better to have more than one proxy, just to play safe…I wish I had more resources…”

(U4): “…I guess I am lucky…I think my eldest daughter will agree to be my proxy…I think she knows well because we took care of my mother who was demented then… but I am afraid I will be under her “tight control” very soon…she wants to get a live-in maid for me…and she also wants me to do this and that…but I am not sure if I want to give up my “freedom” yet…”

4. Discussion

Evidence shows that ACP is not only preparing for incapacity but also preparing for death [57]. Furthermore, having one proxy does not necessarily prevent conflicts among family members and or between the physician and the family [68]. To summarize the participants’ concerns in ACP-D, except in the case of (M3) which may imply difficulties in family relationships, it is obvious that the unmarried group had much more concerns and worries over the health proxy issue than the married group. However, having potential proxy in mind does not mean family consensus and this may create complications at future end-of-life decisions and this “risk” is shared by both (M1) and (M3). It is worth noting that among all participants, (M2) was the only one that had communicated his care wish with his family. For ACP-D, it is only through good family relationships, constant communication and reinforcements about one’s own care wishes, as in (M2)’s case, in order that the future risk of family disputes in ACP-D could be minimized.

4.1. Common Fears and Needs in ACP-D

Common fears in ACP-D included the fear of no one understanding his/her care wishes or needs as in the cases of M3, U1, U2, U3. In addition, there was also fear of no or not enough (number of) health proxy (M3, U2, U3) and the fear of no family consensus (M1, M3). The fear of running out of time as well as the fear of loss of self was most common as shown in the cases of M3, U1, U2, U3, and U4. One factor contributing to the difficulties in identifying the proxy lies in the “high expectations” of the older adults. The high qualifications of “the ideal proxy” also make it hard, both for the married as in the case of (M3) who was...
uncomfortable in appointing her spouse or adult children as proxies as, in her view, none of them understood her needs. This also applied to the unmarried group without adult children. The fact that both (U2) and (U3) mentioned they had potential proxies but (U2) worries are “may not be up to her standard” and (U3) mentioned needing more than one proxy to “play safe”.

4.2. Critical factors in effective ACP-D Communications

For effective ACP-D, the practice experience in this pilot project suggested some critical factors in ACP-D communications for an allied healthcare professional or family member involved in ACP-D. These include the following: knowledge on different stages of dementia including pre-clinical stages in dementia [49]. Awareness of the patients’ fear and skills to reduce stigma; competencies include counseling skills, advanced communication skills in breaking or endorsing bad news as well as essential skills in interacting with families and all stakeholders [17].

The following critical factors in ACP-D communication, classified as “H.E.A.R.T.” were identified in the communication process between participants and the senior clinician. They were namely Hope, Empathetic curiosity, Autonomy, Resources and Timing:

4.2.1 “Hope” was mentioned in M3 and U2, as it is most important to balance hope and fears in ACP-D [14]. Individuals experiencing cognitive deficits could become depressed as a reaction to recognizing their losses and poor prognosis [28]. As such, ACP-D professionals should recognize their clients’ fears and anxiety and provide hope to counter their fears. Hope can be achieved by finding positives, coming to terms and seeing possibilities [19].

4.2.2. “Empathetic curiosity” is underpinned by the core skills of empathic listening and maintaining a curious attitude and can be facilitated by linking curious questions to the non-verbal disruptions in body posture and conversational flow [41]. Furthermore, empathetic curiosity is also a perspective we take to focus our attention of the perceptual experiences of people with dementia and in order to establish common ground for meaningful communication at different stages of dementia care [42]. In ACP-D, older adults need to communicate with families and their information and emotional needs also need to be addressed [68]. Empathetic curiosity would be helpful in case M1, to understand the family dynamics, in order to build family consensus on important ACP-D decisions and cases M3, U1, U2, U3 in helping older adults explore potential proxies.

4.2.3 “Autonomy” is important in order to protect the older adults’ sense of dignity, esteem, competency and desirability. This was important in ACP-D and an obvious need in the case of U4. Furthermore, it was also worth noting that the “lucky one (U4)” among the unmarried group whose daughter had experience in taking care of the grandmother who was demented, had now agreed to act as the proxy for the mother. Yet, the agreeing to do ACP-D seems to be associated with “giving up of one’s freedom”, which was understandably a very difficult decision for (U4). Finally, both groups unanimously agreed that ACP-D was very important in order to assure their quality of life at end-of-life and or if demented. This finding also echoes with Sinclair et al., (2016) as autonomy was among the consensus items in ACP-D discussions [56].

4.2.4. “Resources” are critical in ACP-D and requires careful and realistic evaluation. In the case of U2 in which her sister-in-law could act as a health proxy and given the severe diabetic condition of (U2) and increasing subjective memory complaints, this older adult was at increasing risk of dementia. The questionable standards for health proxy needed to be re-examined before easily “ruling out” some of the possible realistic options of health proxy. In addition, case U3 also mentioned resources and she needed to confirm whether or not her good friend was willing and able to act as health proxy in ACP-D.

4.2.5. “Timing” of ACP-D could be tricky, as mentioned in the cases of U1 and U2. ACPD is similar to ACP in a sense that both are meant to protect the quality of life of older adults but ACP in dementia requires that the patient still has mental capacity [52] which makes ACPD a much more complicated issue. Discussion with families prior to a health crisis is much more efficient and qualitatively better than discussion and making decisions during a crisis [24]. In practice, discussion around end-of-life issues may be nonexistent or start too late [52, 65]. Starting conversations with both the patient and family about ACP at an early stage would initiate an ongoing process for the patient and the family focusing on the patient’s perspectives and wishes [14, 62].
5. Conclusions

5.1. Implications for Allied Healthcare Professionals

It is important for allied healthcare professionals to bear in mind that everyone is an individual with a different history and each family has its own culture and communication pattern. ACP-D is about the acceptance of reality and mortality for all of us, including professionals. ACP-D process is challenging and rewarding and the learning will never end. ACP-D is undertaken at a time of crisis and social work may be the discipline with the most desirable characteristics and skills for this ACP-D facilitator, with its abilities to support people with dementia across a range of systems [40]. This challenge is not just for social workers working in services for the elderly or in the medical field, it is also for allied healthcare professionals with other target groups and other service settings because they will still encounter aging-related issues among their clients in their caseload, and the challenges are further magnified by diseases like dementia, with progressive intellectual and functional losses, possibly coupled with psychiatric and mood disorders [31].

5.2 Implications for Family members

According to the 7 Stages in Alzheimer’s disease Reisburg’s Functional Assessment Staging (FAST) in 1988 [49], older adults with Subjective Cognitive Impairment at Stage II may feel some memory lapses, feeling fearful and doubting if this is part of normal aging. Over 10% of community-dwelling subjects over the age of 70 years suffered from very mild and mild dementia and need public education about memory impairment [35]. Lacking evidence-based education on successful aging and dementia prevention, fear of older adults may increase as they age. Stage III where there is mild decline in memory loss but the person may still choose to keep these problems as one’s own secret due to stigma or fear [50, 53] and this stage may last for up to 7 years [48]. At stage III (Mild Cognitive Impairment, MCI), objective evidence of memory deficits are found in older adults and they have problems with complex tasks. However, their MMSE are within 24 – 28/30 and they still have the mental capacity to exercise their own autonomy. This is the stage whereby family members may notice memory deficits of older adults. Given the aging prevalence in Hong Kong, it is of great importance that adult children, spouses and potential proxies learn about the symptoms, disease trajectory and the critical factors in ACP-D communications, H.E.A.R.T., in order to help older adults in a caring, supportive, knowledgeable and last but not the least, a timely manner.

5.3 Recommendations

The U.K. National Dementia Strategy envisaged that everyone who comes into contact with older people will be required to have some knowledge of dementia and the way to transform the quality of dementia care would be through minimum dementia training for all staff as well as specialist training for professional and general practitioners [29]. The dementia studies at the University of Bradford offers a range of university awards informed by an active program of research and knowledge transfer, including short courses and consultancy with different learning outcomes [18]. It is self-evident that in order to transform dementia care, we need people who can think critically about what is currently provided and, drawing on the rapidly developing evidence base, envisage and implement what is needed in its place [18]. Relevant training for practicing as well as future social workers would be most beneficial for the better quality-of-life for our elders in our rapidly aging society.

In Hong Kong, ACP-D communications could take place in different health settings and for different stages of dementia patients and families. The main limitation of this study is the small sample of 7. Future research on communication needs for different vulnerable groups such as the unmarried are recommended. Moreover, the participants fall mainly into the Subjective Cognitive Impairment (SCI) group only, future research is recommended for different stages from pre-dementia to end-of-life patients and across the social service settings in order to fully explore the needs of the service users with dementia and their family members; as well as the training needs of the human service professionals.

6. References


a national workforce dataset. Aging & Mental Health, 16, 110-118.


