GeriCare: Advance Care Planning – A survey of views of healthcare workers and residents of nursing homes in Singapore

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Introduction and Aim

Ability to exercise autonomy in health care is increasingly imperative for individuals at the end-of-life, as deterioration of mental and physical functions may lead to a time where a person can no longer express their preferences[1]. Advance Care Planning (ACP) involves open conversations with loved ones about future care and treatment, and allows the decision to stand when one becomes cognitively impaired. The GeriCare@North programme is funded by the Ministry of Health, Singapore, to develop partnerships between an acute hospital and nursing homes located in the proximity of the hospital to enhance care. Part of the programme entails equipping the nursing homes (NHs) with skills and resources to empower NH residents to communicate their wishes on future care.

The hospital's ACP Office provided training for nursing home staff of seven nursing homes based on the content by the Respecting Choices programme[2]. To date, the implementation of ACP in nursing homes has been minimal and this topic is not widely researched[3]. This study aims to explore ACP experiences, perspectives, and roles within ACP, to guide quality improvement initiatives and create resources for long-term care homes.

Materials and Methods

This is a mixed methods descriptive study. Surveys with both structured and open-ended questions were conducted for 24 NH staff and 24 residents of seven NHs from April to August 2015. Purposive sampling was employed.

The surveyor tried to elicit participants' general attitudes towards ACP, including barriers and facilitators. Each survey took approximately 1 hour and was conducted in the nursing home where the resident resides in or the healthcare worker works at. Before the survey was administered, the participants were each given a short description of the concept of ACP.

Descriptive statistics were computed for the characteristics of the participants and the scores on the questionnaires regarding their opinions. Responses from the survey were audio-recorded and open-ended responses were transcribed verbatim by the surveyor and analyzed using thematic content analysis[4]. Significant statements were extracted, and categories that conveyed the essential meaning of the participants' experiences were formulated. Statement fragments with similar codes and categories were grouped into themes. All findings were discussed with and validated by the other researchers at a meeting dedicated to this study.

Results

Characteristics of nursing home residents and the healthcare workers are shown in Table 1 and 2 respectively. Slightly more than half of the NH staff (54%) had conducted at least one ACP session, while none of the NH residents had completed an ACP document.

Table 1. Characteristics of nursing home residents

Characteristics	Participants, N=24 n (%)
Age (range)	71 (36 – 98)
Gender	
Female	17 (71)
Ethnicity	
Chinese	19 (79)
Indian	13 (54)
Malay	8 (33)
Religion	
No religion	10 (42)
Buddhist	6 (25)
Christian	5 (21)
Roman Catholic	2 (8)
Muslim	1 (4)
Education	
No formal education	12 (50)
Primary	6 (25)
Secondary	3 (12)
Tertiary	3 (12)
Resident Assessment Form	
Cat 1	0 (0)
Cat 2	3 (12)
Cat 3	16 (67)
Cat 4	5 (21)

Table 2. Characteristics of healthcare workers

Characteristics	Participants, N=24 n (%)
Age (range)	40 (27 – 60)
Gender	
Female	18 (75)
Nationality	
Singapore	10 (42)
Philippines	9 (38)
Chinese	2 (8)
India	2 (8)
Myanmar	1 (4)
Religion	
Christian	10 (42)
Roman Catholic	5 (21)
Hindu	4 (17)
No religion	2 (8)
Buddhist	1 (4)
Muslim	1 (4)
Designation	
Staff Nurse	10 (42)
Nurse Manager	4 (17)
Nursing Aide	3 (12)
Administrator	2 (8)
Enrolled Nurse	2 (8)
Manager	1 (4)
Medical Social Worker	1 (4)
Nursing Director	1 (4)
Conducted at least one ACP	13 (54)

Quantitative Results

Table 3. Quantitative responses

Question	Nursing Home Resident n (%)	Healthcare Worker n (%)
1. Would you like to make an ACP for yourself in the future?		
Yes	10 (42)	23 (96)
No	7 (29)	1 (4)
Unsure	7 (29)	0 (0)
2. Who do you think should decide on your (resident's) care?		
I (Resident) should decide on my (their) own care.	7 (29)	24 (100)
My (Resident's) SDM, healthcare workers, and I (resident) should decide on my (their) care.	7 (29)	0 (0)
My (Resident's) SDM and I (resident) should decide on my (their) care.	2 (8)	0 (0)
Healthcare workers and I (resident) should decide on my (their) care.	2 (8)	0 (0)
I (Resident) should let my (their) SDM decide on my (their) care.	2 (8)	0 (0)
I (Resident) should let my (their) SDM and healthcare workers decide on my (their) care.	2 (8)	0 (0)
I am not sure.	3 (12)	0 (0)
3. What are your fears and concerns before you make (conduct) an ACP?		
I may become very emotional.	4 (17)	6 (25)
I may upset my (resident's) family.	3 (12)	11 (46)
I may have problems talking about it.	2 (8)	7 (29)
I may not have enough knowledge to talk about it.	0 (0)	6 (25)
I may upset the resident.	Not Applicable	11 (46)
I have no time.	Not Applicable	4 (17)
I am not remunerated for it.	Not Applicable	1 (4)

Results (Cont'd)

Table 3 (cont'd). Quantitative responses from survey

Question	Nursing Home Resident n (%)	Healthcare Worker n (%)
4. When do you think would have been a good time to talk about ACP?		
When I am (resident is) well and healthy	8 (33)	16 (67)
When I have (resident has) chronic diseases but am (is) of stable health	8 (33)	12 (25)
When I am (resident is) sick and require(s) much medical care in the hospital	0 (0)	3 (12)
When I have (resident has) a high chance of dying over the next one year	2 (8)	5 (21)
5. Where do you think would have been a good place to talk about ACP?		
In the nursing home	14 (58)	11 (46)
In the hospital	7 (29)	3 (12)
At the resident's home	2 (8)	12 (25)
In the hospice	1 (4)	1 (4)
6. The most important guide for the surrogate in making decisions for you (resident) when you (they) lose decision-making capacity should be based on:		
My (Resident's) best interests	19 (78)	11 (21)
My (Resident's) values	5 (21)	3 (12)
My (Resident's) wishes	0 (0)	16 (67)

Qualitative Results

The themes (Table 4) generally reflect the experience of multiple individuals. However, the perspectives shared by fewer individuals were also presented to document particularly salient viewpoints.

Table 4. Themes and representative comments formed from open-ended responses

Theme	*Representative comment*
Finding the individual	"There are no other alternatives. If the doctor wants you to feed this way (nasogastric tube feeding), you have to be fed this way, because you will die if you don't. Look at those people in level 3, were they given a chance to decide? … Once you remove it (nasogastric tube), the nurse would insert it back, or they tie up your hands and legs." (NH resident)
Conversation	"They (some ACP facilitators) rush [through ACP]… They wouldn't even have time to reflect if this (medical intervention) happens to them, whether they like it or not… I think we should give the residents ample time, you know, to think…" (Nurse Manager, General ACP-trained Facilitator)
Trust & Rapport	"Just treat the doctor as god, and he will decide whether I live or die. It doesn't matter for me, anyway." (NH resident) "Because anxiety is a genuine emotion and I think we need to first address that before we can make people sign the document… Then they can actually carry out their duty to honor the wishes your resident has indicated. [But] first you need to take care of that (anxiety)." (Medical Social Worker, PPC Facilitator)
Family	"If there is no treatment then just let me die. By that time, I would have been useless and truthfully speaking I have no more liabilities… If I leave, I won't be a burden to my family…" (NH resident) "She (a NH resident's wife) is not too sure whether she wants to stop it (withdrawing the life-sustaining intervention). "If I stop, I am killing my husband." Actually ACP has been done…You can actually go through the whole process of going through [and] when they actually arrive at that point in time the struggle is genuine." (Medical Social Worker, PPC Facilitator)
Readiness & Acceptance	"There is nothing to be emotional about. Once you are old, you will fall sick. Everyone have to take this path. Don't have to think about it." (NH resident) Because I am taking care of him (a NH resident) all the time… then why does he prefer to pass away? He still has a home to go back to. He's got family." (Staff Nurse, PPC Facilitator)

Discussion and Conclusion

Based on the quantitative results, discrepancies between the choices made by the healthcare worker and that of the resident's were found. Emergent themes identified ACP as a meaningful platform to empower NH residents to express their care preferences but revealed that in order to establish this platform, allowing time and preparing the resident and family for the conversation are necessary. The healthcare workers related the concept of self-determination with dignity and seeing each resident as unique. They emphasized that their role as a facilitator requires relational skills to achieve a shared understanding and meaning, and pointed out deficiencies in the current training. There is also a need for the healthcare workers to view ACP as more than just a 'tick box' exercise. According to a study[5], ACP discussions are effective when they encompass rich conversations that are not limited to the issue of resuscitation and involve meanings and fears around illness and dying, preferences for after death care, and spirituality.

Most of the NH residents displayed passivity towards deciding for their own care, and held the misperception that only physicians possess the authority to make care decisions when they lose their decision making capacity. Although the residents lacked adequate understanding of ACP, they were ready to talk about care before death and dying.

Findings from this study underscore positive attitudes towards ACP, as well as important concerns expressed by the healthcare workers such as fear of upsetting the resident and family members. ACP has the potential to facilitate valid expressions of wishes that would not have been known without these conversations. However, these conversations must be appropriately timed, and done with great sensitivity and in context. More in-depth training on communication skills and targeted engagement were identified as important in encouraging participation in conversation among the residents and families. In addition, healthcare workers need to understand that death is the inevitable end to life, before they can help residents see beyond their fears and make reasonable treatment choices.

More public education on ACP is necessary in Singapore, to advocate for individuals' rights to voice their wishes and to cultivate willingness and openness to talk about care before death and dying between residents and their family members.

References

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