

Letter to the Editor

Decision-Making in Dementia Care: a Qualitative Study of Chinese Family Caregivers in Singapore

Dear Editor,

In 2003, the prevalence of dementia in individuals aged ≥ 60 years old in Singapore was 5.2%;¹ in a recent epidemiological study, it had risen to 10%.² As the population ages, an increasing number of people will be caring for their loved ones with dementia. In many Asian countries, family caregivers are intimately involved in the care of older adults. In Singapore, family caregivers struggled with their caregiving responsibilities and there is a high prevalence of depressive symptoms among them.^{3,4} It has been found that problematic family environment and lower levels of decision-making satisfaction can have a cumulative effect on caregiver depression.⁵ Decision-making satisfaction was described as how happy family members were with regards to the discussion related to care planning.⁵ The proposed Path Model from a general stress paradigm posited that caregiving context and family environment might have an indirect effect on depression through decision-making satisfaction.⁵ The decision-making process is suggested to have the potential to engender additional strain on family caregivers.⁵

A recent local study suggested that most individuals with early cognitive impairment declined any discussion on advanced care planning (ACP).⁶ Decisions on care delivery are often made by family caregivers on behalf of persons with dementia (PWD) who lacked the mental capacity to do so. In elderly individuals with cancer or organ failure, factors such as an understanding of their prognoses and ACP have been shown to influence their acceptance of palliative care services and quality of life.^{7,8} In PWD, cognitive decline poses specific challenges in their understanding of prognosis and ACP. Consequently, family members often report major barriers and psychological distress in making care decisions.⁹

To date, most studies on dementia caregiver interventions in non-Western populations had emphasised behavioural interventions and their impact on the quality of life of caregivers.¹⁰ There is a dearth of literature on how decision-making roles in dementia caregivers impact their well-being and caregiving role. To the best of our knowledge, this was the first qualitative study of decision-making among family caregivers of PWD in

Singapore. With an understanding of these challenges, appropriate support can be rendered to family caregivers and PWD in making care decisions.

Materials and Methods

Patients who were referred to the memory clinics in our organisation with a diagnosis of dementia and had a family caregiver were screened. Informed consent was obtained and a questionnaire was used to collect their sociodemographic data. Information on diagnosis and severity of dementia was determined from clinical notes. The study was approved by the Centralised Institutional Review Board (CIRB 2013/583/A).

Interviews with caregivers were conducted by the Principal Investigator (PI) and were guided by questions on diagnosis, treatment and care decisions (Fig. 1). Each interview was digitally recorded and transcribed verbatim. Thematic analysis was used to identify themes in decision-making.

The initial themes were summarised by the PI and the data was coded and analysed using Atlas.ti, version 8.0 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Data collection ceased after no new themes were found. A total of 14 participants were included in the study.

Results

The clinical variables and sociodemographics of 14 PWD and their caregivers are summarised in Table 1. All the participants were Chinese in ethnicity. Almost all PWD were women and most of them had moderate to severe dementia. Most caregivers agreed with the diagnosis of dementia; however, only 3 of them endorsed dementia as a terminal illness. The qualitative analysis identified 4 primary themes that are described in the following sections.

Decision to Reveal Diagnosis of Dementia

Nine caregivers wished their loved ones to be informed of the diagnosis of dementia. Family members felt that they should be open with them because they had the right to know and would cooperate better with treatment after they were informed of their diagnosis.

<p>The diagnosis</p> <ol style="list-style-type: none"> 1. Does your loved one have a memory problem? 2. Does your loved one have “dementia”? 3. What else would you like to know? 4. When would you like to know? 5. How do you wish to find out? 6. Is your loved one in the mild, moderate or severe stage of dementia? 7. Does s/he have a terminal illness? <p>Information about dementia</p> <ol style="list-style-type: none"> 8. Do you wish your loved one to be informed of the diagnosis of dementia? Why? 9. How should it be communicated? 10. What is important to mention? 11. Who should tell the patient? <p>Care and treatment options</p> <ol style="list-style-type: none"> 12. What care and treatment options are there? 13. How do you find out about them? 14. Why would you consider these options? <p>Making the decision</p> <ol style="list-style-type: none"> 15. What is your greatest fear/concern with regards to the care of your loved one? 16. What are other decisions you will have to discuss with your loved one? 17. If you have not done so, why? 18. When would you discuss with your loved one? Why? 19. Who should be the one to discuss with your loved one? Why? 20. In the event of poor feeding, would you consider tube feeding? Why? 21. If s/he needs to be restrained to ensure safety, would you be agreeable? Why? 22. Does your loved one have a living will? If yes, who made the decision for the living will? Why do you think it is important? If not, do you intend to help your loved one do so? Why? 23. Would you be comfortable to discuss funeral arrangements with your loved one before s/he becomes too forgetful? Why? 24. What are your views about hospital admission for your loved one with dementia? 25. What would help you make your choices easier?

Fig. 1. Interview guide. The questions served as a guide to gather information on diagnosis, information about dementia, care and treatment options and care decisions that family caregivers must make currently and in future. The guide was designed to understand the experiences of family caregivers and to identify difficult decisions that were made by them, and the enablers and barriers to the decision-making process.

In the words of caregiver 7, “At least get her mentally prepared. At least she can face, we don’t need to hide from her. So she can actually accept the facts . . . so she will accept. At least prepare and accept the facts that there will be some difficulty in handling her living style here and there.”

Caregivers of PWD 2, 4, 6 and 13 chose not to disclose the diagnosis (their sociodemographic data are summarised in Table 1). They feared that PWD would not be able to accept the bad news and this could worsen the situation.

Challenges in Making Care Decisions

About half of caregivers would not discuss future care decisions. There was a general perception that PWD would trust them to make decisions on their behalf. A total of 3 secondary themes were identified: 1) difficulties in understanding the life-limiting nature of dementia, 2) perceived refusal of PWD to cooperate with treatment and 3) helplessness of caregivers with regards to caregiving.

According to caregiver 3, “Maybe because her type of dementia she’s the mild type in the sense she’s not the aggressive type so it’s easier to handle . . . And that she must really accept what we say. When we tell her you have not bathed, she kept on insisting she had bathed . . . She has to accept certain things she can’t remember actually.”

Decisions to Be Made in Caring for PWD

The common decisions that were highlighted involved finances, freedom to leave home and admission to a nursing home or dementia day care centre. Difficult decisions were identified as those that related to care in the final phase of dementia, namely nasogastric tube feeding, physical restraints, hospital admission and funeral arrangements.

Caregivers also expressed their preference to let nature takes its course. They were unfamiliar with options such as lasting power of attorney (LPA) and ACP, and would prefer to follow the recommendations of the physicians. Caregiver 7 described it as “Until that stage, then we can decide.”

Support for Family Caregivers to Care for PWD

Two areas were repeatedly highlighted by the participants: practical care of their loved ones with dementia and more support in understanding the care needs of PWD.

In the words of caregiver 12, “Actually at the beginning, as soon as she is diagnosed with dementia, it’s good to have a relatively good understanding of the condition as well as the kind of care giving that is necessary. And the kind of help that can be given to the caregiver . . . yah, so I guess it’s informing us with that compassion as well not just something that is very clinical. So I guess that helps

Table 1. Sociodemographic Data and Clinical Characteristics of PWD and Their Caregivers

Number	PWD							Caregiver				
	Dementia Type	Dementia Severity (MMSE Score)	Age (Years)	Gender	Marital Status	Number of Children	Education	Religion	Relationship	Age (Years)	Marital Status	Education
1	Mixed	Mild (21)	84	Male	Married	3	Secondary	Taoism	Daughter	57	Single	Tertiary
2	AD	Moderate (19)	89	Female	Divorced	4	Tertiary	Buddhism	Daughter	55	Married	Secondary
3	Mixed	Moderate (13)	84	Female	Widowed	2	Secondary	Christianity	Son	59	Widowed	Tertiary
4	Mixed	Moderate (17)	79	Female	Divorced	4	Primary	Buddhism	Son	58	Married	Secondary
5	AD	Mild (23)	67	Female	Single	0	Primary	Taoism	Sister	59	Married	Secondary
6	Mixed	Moderate (10)	78	Female	Widowed	4	Nil	Christianity	Son	50	Married	Tertiary
7	Mixed	Severe (5)	78	Female	Widowed	6	Nil	Buddhism	Son	47	Married	Tertiary
8	Mixed	Moderate (16)	77	Female	Married	2	Primary	Nil	Son	49	Married	Tertiary
9	AD	Moderate (11)	87	Female	Widowed	7	Nil	Nil	Son	59	Married	Secondary
10	Mixed	Moderate (13)	85	Female	Widowed	5	Nil	Taoism	Son	49	Married	Secondary
11	Mixed	Moderate (17)	81	Female	Married	1	Nil	Nil	Daughter	42	Single	Secondary
12	Mixed	Moderate (13)	85	Female	Widowed	5	Nil	Christianity	Daughter	48	Married	Tertiary
13	AD	Mild (20)	82	Female	Married	2	Secondary	Christianity	Spouse	80	Married	Tertiary
14	AD	Severe (0)	66	Female	Married	2	Secondary	Christianity	Spouse	66	Married	Secondary

AD: Alzheimer's disease; MMSE: Mini-Mental State Examination; PWD: Persons with dementia

because you will be at a point of time where it's just so emotionally difficult”

Discussion

To the best of our knowledge, this is the first local qualitative study that investigated the decision-making process amongst Chinese family caregivers of PWD. As dementia progresses, medical practitioners often rely on family members to understand and choose treatments with assumed accuracy. In our study, most family caregivers supported the decision to discuss the diagnosis of dementia with patients, but half of them chose not to discuss future care plans and decisions. A common theme that emerged in our study was the belief of caregivers that their loved ones with dementia would entrust them with this role. The value of familism—needs of the family are perceived as more important than those of individual members—is an entrenched belief in Asia.^{11–3} The need to maintain family harmony and the influence of Confucianist and Taoist ideas that family members would be entrusted with the care of their ailing elders¹⁴ might be possible reasons to explain this trend that was observed in our study.

Findings in the literature on decision-making and family caregiving of elderly loved ones in non-Asian settings suggested that families tended to rely on family members—rather than professionals—in making elder care decisions.^{15–6} A previous study had shown that elderly Singaporeans were reluctant to engage in discussions on end-of-life (EOL) care and preferred their physicians to take on the role of surrogate decision-maker on their behalf.¹⁷ Similarly, in our study, family caregivers preferred their doctors to help them with making critical decisions in the last stage of dementia.

In the elderly, the take-up rate for discussions on ACP was previously noted to be modest at 38%.⁶ It would not be a surprising finding that family caregivers in our study had encountered difficulties in discussing care decisions with PWD. Previous studies also showed that the lower take-up rate for ACP was associated with more advanced cognitive impairment.^{6,8} Consequently, it would be pertinent to encourage and engage family caregivers to initiate ACP with their loved ones who were diagnosed with early-stage dementia.

Another common theme was that family caregivers preferred to deal with the challenges of care when they surface later. Half of our participants believed that their loved ones with dementia would trust them to make decisions on their behalf. However, family members were not familiar with ACP and LPA, and would defer critical decision-making to their doctors. In the United Kingdom, a study had shown that both PWD and their caregivers showed marked uncertainty about ACP

and EOL treatment preferences even when the caregiving relationship was perceived to be good.¹⁸

In our study, the concept of dementia as a terminal illness was not easily accepted by family caregivers. Consequently, they did not see the necessity to engage PWD in timely discussions when the latter still retained their decision-making capacity. Other studies had also highlighted that both professional¹⁷ and family caregivers¹⁹ did not view dementia as a terminal illness. This might have contributed to neglect in discussing EOL care for PWD and their care providers.^{18,20} In our study, the common difficult decisions were identified as those that related to EOL care, namely nasogastric tube feeding, physical restraints and hospital admissions.

The lack of understanding of dementia as a terminal illness is an issue that must be addressed in a sensitive manner. A secondary theme that was found in our study was the feeling of helplessness experienced by family caregivers in their caregiving role. At the same time, they also yearned for more support to understand the care needs of their loved ones. Consequently, family members would benefit from early and continued practical and psychological support in their journey towards EOL care in the dementing process.

A limitation of this study was that it recruited family members whose loved ones had moderate to severe dementia and caregivers were mainly children of PWD. Consequently, the results on the challenges in decision-making might not be generalised to other familial caregiving relationships. As we had difficulty recruiting non-Chinese family members into the study, the results might also not be relevant to other ethnic groups in Singapore.

Conclusion

Besides their feeling of helplessness and uncertainty in making treatment decisions on behalf of PWD, family caregivers tended to rely on medical practitioners to make difficult EOL care decisions. They also lack understanding of dementia as a terminal illness^{17,19} and expressed marked uncertainty about ACP.¹⁸ Discussions about difficult decisions were also not perceived as urgent or necessary. Efforts should be made to raise awareness that dementia is a life-limiting illness and to facilitate discussions of ACP in a sensitive manner. With findings of low take-up rate for ACP that followed a decline in cognitive function in Western populations,^{6,7} discussions with PWD and their family caregivers on ACP during the early stage of dementia—with the involvement of medical practitioners—could help them to make informed decisions on future care that include ACP and EOL care.

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