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Uptake of a newly implemented advance care planning program in a dementia diagnostic service

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Abstract

Background: advance care planning (ACP) provides a framework for discussion and documentation of future care preferences when a person loses cognitive capacity. It can assist people in the early stages of dementia to document their preferences for care at later stages of the illness.

Method: a three-stage project introduced ACP to clients with mild cognitive impairment (MCI) or recently diagnosed dementia and their families through a specialist memory clinic. Over 8 months, all English-speaking clients ($n = 97$) and carers ($n = 92$) were mailed a survey assessing completed documentation for future care; understanding of the principles of ACP and

willingness to get further information about ACP (Stage 1). Participants wanting more information were invited to a seminar introducing the ACP program and service (Stage 2). Participants wanting to complete ACP documentation could make an appointment with the ACP clinicians (Stage 3).

Results: forty-eight (52.2%) carers and 34 clients (35.1%) responded to the survey. Most clients (62.1%) and carers (79.1%) expressed interest in ACP, and 78.6% of clients and 63.6% of carers believed that clients should be involved in their future medical decisions. Nine clients (26.5%; diagnoses: MCI = 5; AD = 3; mixed dementia = 1) and 9 carers (18.8%) attended the seminars, and 2/48 (4%) carers and 3/34 (8.8%) clients (diagnoses: MCI = 2; AD = 1) completed ACP.

Conclusion: despite initial interest, ACP completion was low. The reasons for this need to be determined. Approaches that may better meet the needs of people newly diagnosed with MCI and dementia are discussed.

Keywords: advance care planning, dementia, mild cognitive impairment, Respecting Patient Choices, older people

Introduction

Advance care planning (ACP) allows people to discuss and document medical treatment wishes for a time when decision-making capacity is lost [1], with the aim of reducing the confusion, burden, stress and conflict that often arises at this time [2, 3]. The Respecting Patient Choices program [4] has been implemented as the local ACP model and incorporates appointment of enduring powers of attorney (EPOAs), refusal of treatment certificates (ROTC) and a statement of choices that are used to guide future treatment. Dementia is an ideal target for ACP as decision-making capacity is likely to be retained at diagnosis but is lost at the time complex medical decisions are required. As capacity is required for some ACP documentation to be legally recognised, limited time is available to complete ACP [5], otherwise treatment decisions will be made without a clear understanding of what the person wanted [6–8].

ACP is relatively new to Australia, and awareness and legislative support is not well developed. In our state (Victoria, Australia), the Medical Treatment Act (1988) allows competent patients to verbally refuse treatment, complete a ROTC and appoint a substitute decision-maker in case of incapacity called a Medical EPOA (MEPOA). The MEPOA can also refuse treatment.

Timely diagnosis of dementia allows the greatest time for ACP to be discussed and plans made while the affected person remains competent [9]. Cognitive, Dementia and Memory Services (CDAMS) were introduced state wide in Victoria in 1997 to provide a specialist, multidisciplinary diagnostic service for people concerned about cognitive deterioration. CDAMS clients complete a thorough health and cognitive assessment and are provided with a diagnosis; information about prognosis, treatment and support options; and strategies for future planning. This is an opportune time to introduce ACP to people with MCI and dementia as they are engaged with the health system and most will retain decision-making capacity, at least in the short term [10].

In this study, we examined whether plans for loss of capacity had been made by CDAMS clients with MCI or dementia. An ACP pilot program was introduced, and we measured support for the principles of ACP and the number of clients and family members who went in to complete ACP documentation.

Methods

Participants

Using convenience sampling, over an 8-month period all English-speaking CDAMS clients diagnosed with MCI or dementia ($n = 97$) and a listed carer ($n = 92$) were mailed a

Table 1. Overview and demographics of clients and carers who participated in the study

	Clients, $n = 34$	Carers, $n = 48$
Age (M (SD))	79.8 (7.8)	65.7 (13.1)
Gender, n (%)		
Female	18 (52.9)	34 (70.8)
Male	16 (47.1)	14 (29.2)
Education, n (%)		
Primary	3 (9.1)	1 (2.2)
Secondary	14 (42.4)	17 (37.0)
Tertiary	16 (48.5)	28 (60.9)
MMSE ($n = 29$) (M (SD))	25.76 (3.96)	
	Range: 12–30	
Diagnosis, n (%)		
MCI	16 (47.1)	
AD	7 (20.6)	
Mixed dementia	8 (23.5)	
Other diagnosis	3 (8.8)	
Previous experience with dementia, n (%) yes	15 (44.1)	20 (41.7)
Interested in ACP seminar, n (%) yes	18 (52.9)	30 (62.5)
Aware of options available, n (%) yes		
Financial EPOA	22 (64.7)	36 (75.0)
Medical EPOA	21 (61.8)	35 (72.9)
Enduring guardian	12 (35.3)	17 (35.4)
Refusal of treatment certificate	7 (20.6)	12 (25.0)
Living with memory loss ^a	7 (20.6)	16 (33.3)
Senior rights (free legal service)	6 (17.6)	10 (20.8)
ACP	8 (23.5)	10 (20.8)
Documentation completed, n (%) yes		
Financial EPOA	9 (26.5)	
Medical EPOA	7 (23.5)	
Enduring guardian	2 (5.9)	
Refusal of treatment certificate	0 (0)	
GPOA	6 (17.6)	
No documentation	13 (38.2)	

MCI, mild cognitive impairment; AD, Alzheimer's disease; EPOA, enduring power of attorney; ACP, advance care planning.

^aLiving with memory loss is an information and support group offered to people with early-stage dementia offered through Alzheimer's Australia.

questionnaire. MCI and dementia diagnoses (predominantly Alzheimer's disease and mixed dementia (Table 1)) were made in accordance with accepted clinical criteria.

Procedure

The project was conducted in three stages.

Stage 1: Following ethics approval, clients and carers were mailed a purpose-designed questionnaire seeking information about demographics; impact of diagnosis; prior experience with dementia; awareness of ACP and its components; and any documentation completed prior to the assessment. Service-related factors and beliefs about ACP and its processes were measured using a 5-point Likert Scale (5—Strongly Agree to 1—Strongly Disagree). A sample is provided in Figure 1.

Stage 2: Respondents were invited to attend a seminar delivered by an ACP clinician experienced in working with people diagnosed with dementia. The seminar introduced ACP, the Respecting Patient Choices program [4] and the type and value of the decisions that can be documented. Attendees provided feedback on the seminar.

Stage 3: Seminar attendees were invited to attend the ACP service to complete ACP documentation. Those who participated provided an evaluation of this stage. This was the final contact with participants.

Results

Stage 1: Questionnaire

Forty-eight carers (52.2%) and 34 clients (35.1%) responded. Clients were older, less educated and more likely to be male

than carers (see Table 1). Carers and clients reported similar prior experience with dementia, and 45% of clients and 43.3% of carers reported regularly thinking about how the diagnosis would affect them in the future.

Table 1 shows that there was a high level of awareness of Financial and Medical EPOAs, but this was not as high as awareness of other options. Despite this, 38.2% of clients had not completed any formal documentation planning for future incapacity (Table 1).

Most clients (78.6%) and carers (63.6%) agreed that clients should be involved in future medical decision-making. Substantial numbers of carers (57.8%) and clients (40.7%) worried about the family making treatment decisions on the clients' behalf. More carers (66.6%) reported being aware of client preferences for future treatment than clients (55.5%), but only 50% of carers and 46.1% of clients reported having discussed these preferences. Most clients (62.1%) and carers (79.1%) were interested in using an ACP service and attending an ACP seminar (clients: 52.9%; carers: 62.5%).

Stage 2: Seminar

Respondents interested in learning more about ACP (clients, $n = 18$; carers, $n = 30$) were invited to an ACP seminar, and 9 CDAMS clients (26.5%; diagnoses: MCI = 5; AD = 3; mixed dementia = 1) and 9 carers (18.8%) attended. Attendees agreed that the seminars were helpful with 86% reporting motivation to complete documentation.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I have received enough information about their/my diagnosis					
I received information about available services at the time of their/my diagnosis					
I worry about/I worry about my family/friends having to face important decisions regarding their medical care in the future					
I do not want important medical decisions to be made in the future without their/my involvement					
I am aware/My family is aware of how I/they wish to be medically treated in the future if I/they are unable to express themselves					
We have discussed what their values and preferences are for life prolonging treatment in the future					
I would be interested in using a service where advance care planning for future treatment options are discussed with us/me and the family:					

Figure 1. Sample questions completed by CDAMS clients and family members in Phase 1 of the project. Both client and family member options are included in each question.

Stage 3: Completion of ACP documentation

Of all respondents, 2/48 (4%) carers and 3/34 (8.8%) clients (diagnoses: MCI = 2; AD = 1) completed ACP documentation, primarily motivated by partners' and legal advice. Participants felt relieved and positive about the program and believed that ACP should be offered through CDAMS. No additional approaches were made to participants to complete ACP.

Discussion

People newly diagnosed with MCI or dementia and their carers supported the principles and objectives of ACP. Most respondents wanted to obtain further information about ACP; however, only 4% of carers and 9% of clients completed documentation by study completion. Whether or not the diagnosis is MCI or dementia does not seem to play a role as the proportion of participants with MCI and dementia remained equivalent through each stage of the study. While 66.6% of carers reported knowing the treatment preferences of the client, only 50% reported having discussed this with the client, and fewer clients reported having this discussion. It is important that these issues are explicitly discussed [6–8] as there can be great disparity in the values and treatment wishes between people and their appointed proxy.

The low ACP completion rate in this study was disappointing, although it was not without precedent for a program introducing ACP for the first time [11]. The low completion rate may be related to a number of factors. ACP readiness can vary according to need [12], and participants may have felt that their current planning was sufficient for their circumstances. Alternately, participants may be in the Contemplation stage of the transtheoretical model [11] and unready to document plans. As the project was conducted within a short timeframe, it is possible that participants did not have time to fully understand the principles and practical aspects of ACP and comfortably complete documentation. Completion rates are likely to increase if ACP is gradually introduced to people over time and allowing for ongoing discussion, the gold standard for increasing ACP completion [13]. It is possible that these results reflect a trend whereby carers of people newly diagnosed with MCI or dementia do not utilise suggested referrals or support services at diagnosis [14]. Equally, some other unexplored patient, family, staff or systemic factors may have contributed to the low numbers completing ACP documentation [15–18]. Importantly, most respondents were interested in ACP and supported its underlying principles.

As CDAMS is an assessment and referral service, clients are only seen a small number of times over a short time period and the opportunity for ongoing dialogue is limited. We used a staged design to engineer the opportunity for ongoing dialogue about ACP, but this appears unsuccessful over the short study period. The results could be viewed as being particular to this study considering that it was conducted

at a single site, with limited resources, and utilised a small, English-speaking convenience sample. The methods and timing of the approach used here, however, do represent a realistic clinical scenario that can be applicable to other settings.

It is difficult to introduce and discuss ACP in a compressed timeframe, particularly considering that locally it is not a widely recognised program. The clinical implication of our findings is that the optimal approach would be to initiate the conversation about ACP in CDAMS and ensure that this conversation continues into primary care with clear pathways to engage with the ACP clinicians through our health network so that people can feel comfortable with the concept and have their queries addressed as they arise. As the program is more widely recognised and better integrated into ongoing clinical care, ACP completion rates should improve. However, future work should conduct a more thorough exploration of factors that influence the decision to complete ACP by people with MCI and dementia.

Key points

- Planning for health care in late stage dementia is important.
- ACP provides a structure for future medical decisions to be made.
- Capacity requirements limit the time available to plan for future medical treatment in dementia.
- People recently diagnosed with MCI or dementia are theoretically in support of ACP.
- Few participants completed ACP.

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Conflicts of interest

None declared.

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Authors' roles

M.L. developed the study and oversaw the collection of data, analysis and preparation of the manuscript. E.R. assisted in the design of the study and recruitment and contributed to the preparation of the manuscript. E.M., D.M. and S.M. all contributed to the preparation of the manuscript.

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Cognition and mortality in older people: the Sydney Memory and Ageing Study

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Abstract

Background: both cognitive ability and cognitive decline have been shown to predict mortality in older people. As dementia, a major form of cognitive decline, has an established association with shorter survival, it is unclear the extent to which cognitive ability and cognitive decline predict mortality in the absence of dementia.