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Audit of advance care planning documentation for Alzheimer's disease in Brunei

Abstract

The documentation of advance care plans in clinical records of speciality clinics in Brunei for Alzheimer's disease was audited. Among the 168 patients with Alzheimer's disease, the median age was 80 years. Two-thirds (106) had moderate-to-severe dementia, of which 9 (8.5%) were on enteral feeding and 64 (60.4%) did not have documented discussions regarding feeding preferences. There were no documented discussions regarding preferences on cardiopulmonary resuscitation in 57 (53.8%), or a proxy decision-maker in 72 (67.9%). Advance care planning in Alzheimer's disease could be improved in terms of initiating discussions and documenting preferences in clinical records, especially for speciality clinics and for those in moderate-to-severe stages of the disease.

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Key words: advance care planning, Alzheimer's disease, cardiopulmonary resuscitation, dementia, enteral nutrition

Introduction

Advance care planning (ACP) is a continuous, dynamic process for decision-making regarding preferences for future treatment and end-of-life care. This requires reflection and dialogues between an individual and relevant parties, including healthcare professionals and loved ones. A qualitative study evaluating the perspectives of people with dementia and caregivers regarding ACP found that many were unaware of the expected trajectory of dementia and the potential decisions they may face in the future [1]. A nationwide

Belgian study found a low rate of patient-driven ACP in dementia, with poor congruence in the opinions of caregivers and relatives [2]. Therefore, it is important to have early ACP discussions and documentation for dementia patients, as their decision-making capacity declines over time.

Brunei is a small, predominantly Muslim country in South East Asia. There is currently no legal framework or legislation related to advance directives or appointment of healthcare proxy decision-makers. Nevertheless, clinicians who discuss these aspects should document patient preferences regarding ACP in the

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clinical notes. A systematic review involving healthcare professionals from Asia found that clinicians overall agreed on the importance of ACP. However, they felt that they had limited knowledge and skills in engaging patients with discussing ACP due to fear of conflicts with family and legal repercussions [3]. The study aimed to assess the extent of ACP documentation in electronic clinical records for dementia patients in Brunei.

Methods

Brunei has a linked national electronic clinical record called Brunei Health Information Management System (Bru-HIMS). All clinical encounters require clinicians to enter an ICD-10 diagnostic code. The Bru-HIMS system was used to extract clinical encounters related to Alzheimer's disease (AD) diagnoses for 2019 and 2020. Their demographic details, speciality clinic attended and dementia severity based on the Clinical Dementia Rating (CDR) scale was obtained. The aspects of ACP evaluated were discussions regarding enteral feeding, cardiopulmonary resuscitation (CPR) and a named proxy decision-maker. For patients with advanced dementia who cannot make an informed decision, documented discussions with a proxy decision-maker regarding future care such as appropriateness of enteral feeding was considered as acceptable ACP documentation for this audit.

Results

There were 168 patients with AD. The median age was 80 (range 60–98), and 58.9% were female. The main speciality clinics attended were geriatrics (61.3%), neurology (22%) and psychiatry (11.3%). Almost half were able to mobilize independently. Two-thirds (106) had moderate-to-severe dementia. Among those with moderate-to-severe dementia, 9 (8.5%) already received enteral feeding, while 64 (60.4%) did not have any documented discussions regarding feeding preferences. There were no documented discussions regarding cardiopulmonary resuscitation in the event of a cardiac arrest in 57 (53.8%), or a proxy decision-maker in 72 (67.9%).

Several examples of documented discussions extracted from the clinical records are as follows:

'Explored with daughter regarding nasogastric feeding because of malnourishment. Explained this will not change the trajectory of her dementia. There is also a high risk of aspiration with her tendency of pulling the nasogastric tube. The daughter was agreeable not for nasogastric feeding.'

'After discussion, the family refused nasogastric tube insertion.'

'Discussed with patient's family regarding ceiling of care in case of sudden deterioration or cardiac arrest. They agree the patient is not for CPR, intubation or intensive care admission.'

'Limited options available because of her age and existing comorbidities. The daughter understood the Do Not Attempt CPR status.'

'ACP explored with the two daughters: the ceiling of care was already previously established. Ongoing aspiration risk and anticipated future rejection of medications. A nasogastric tube is not recommended, and approaching comfort cares in the terminal stage.'

'ACP attempted to be explored. The daughter was overwhelmed and not keen to discuss as she recently lost her father.'

Discussion

Overall, most AD patients were seen in speciality clinics, with a large proportion in moderate-to-severe stages of the disease. Improvements are required in terms of initiating discussions and documenting the plans in clinical records. There are several possible reasons for limited ACP uptake. Firstly, Brunei has a multiracial multi-ethnic community, thus cross-cultural considerations may be relevant to ACP discussions. A study found that older people from various ethnicities and religions may not appreciate the importance of ACP or a need for a contingency plan in severe illness; citing their future is best left to fate or God [4]. Improved awareness of ACP among healthcare professionals and the public may be required. Training and educational resources may be required to prepare clinicians for ACP discussions [5]. Specifically allocating time in speciality clinics dedicated to ACP discussions should be considered for advanced dementia patients. Roadshows and the use of social media to publicize ACP may help overcome the stigma and normalize ACP discussions within the community. A limitation of this audit is that specific details related to the quality of the ACP discussions or documentation regarding enteral feeding, CPR and proxy decision-makers have not been evaluated.

Conclusions

ACP should be considered a routine part of clinical consultations for people living with dementia. ACP alleviates the emotional impact on patients and caregivers and improves end-of-life care for those with severe illnesses [6]. This audit highlights the need for

improvement in terms of ACP initiation and documentation.

Declaration of conflict of interests

The authors declare that there is no conflict of interest.

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