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Commentary

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Addressing Decision Making on End of Life Care for People with Dementia

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Abstract

Dementia affects approximately 36 million people worldwide and the number living with dementia is expected to increase to 66 million by 2030 [1]. Dementia is recognised as a public health priority which urgently needs attention by the World Health Organisation [2]. Despite recent national and international policy initiatives, people with dementia continue to receive invasive treatment such as artificial nutrition and hydration and inadequate care towards the end of their lives [3]. In our scoping review of decision making and advanced care planning for people with dementia, we outline some of the challenges of decision making that people with people with dementia, their families and health professionals face in talking about a complex and sensitive issue.

Keywords: Dementia; End of life care; Death and dying; Proxy decision making

Introduction

While there has been increasing attention upon dementia and end of life care by policy makers and international governments, there has been less focus on the complex physical and psychological needs of dementia. As a consequence, people with dementia may be subject to interventions that they might not otherwise have wanted (resuscitation, artificial nutrition and hydration) if the condition is not recognised as being terminal. Including people with dementia and their families in planning for end of life care can provide opportunities to review and initiate appropriate palliative care.

The WHO [2] describes Advance Care Planning (ACP) as a discussion about preferences for future care between an individual and a care provider in anticipation that the person's condition will deteriorate. Some of the benefits of having this discussion are that it provides an opportunity to discuss and later, initiate timely palliative care [4]. With dementia, it is suggested that these discussions should take place in the early stages of the disease [5]. However, the topic can be distressing for some people and their families especially when health and social care professionals are challenged by the lack of interpersonal skills or training to facilitate such a sensitive discussion or are reluctant to assume responsibility for discussing ACP [6].

We conducted a scoping review studies which have explored decision making processes associated with people with dementia and their families. Eligible studies had to report on decision making at the end of life, who was involved in this discussion and how the discussion was initiated (health care professional, the person with dementia, the family member) [7-11].

In this review of the evidence concerning EoLC for people with dementia and the decisions which influence care at the end of life. Our review was guided by three research questions a. Who is involved in the decision-making process? b. How are decisions made concerning EoLC and what is the outcome in facilitating a good death? c. In what way do systemic factors impact upon EoLC?

Twenty five eligible studies reported on planning for end of life care and the decisions made by and for people with dementia. The studies demonstrate that there are a number of unique challenges that need to be addressed to ensure that people with dementia receive appropriate, adequate and effective care towards the end of their life.

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