

COMMENTARY

Talking about future decision-making capacity and advance care planning in diagnosis disclosure of dementia

Dementia has become a significant challenge to global health and social care due to an increasing number of people diagnosed with the condition. Although there has been substantial advancement in diagnostic biomarkers for dementia, the diagnosis of dementia is still uncertain and difficult in real clinical encounters (Bradford *et al.*, 2009). The course of dementia is generally perceived as distressing, involving the person's declining cognitive functions and increasing dependency levels. Therefore, diagnostic disclosure of dementia to the person and their family is considered difficult for healthcare professionals (HCPs). The disclosure is even more challenging when it comes to the fact that there is no cure for dementia, and public understanding of dementia as a life-limiting condition remains poor (Cipriani and Borin, 2015; Lamahewa *et al.*, 2018). Provision of information about available support alongside the diagnosis is critical to throw light on how patients and families can continue living well with dementia; however, this process does not always happen (Dooley *et al.*, 2018). The discussion on available support, treatments, and preferences for the future needs to be done timely before the person with dementia becomes less able to be involved in their care plan and decisions, which often leads to suboptimal care for the person with dementia in later stages.

Yates *et al.* (2021) conducted a systematic review to identify common practices for diagnosis disclosure of dementia and challenges attached to it from different individuals involved. They found that the process generally causes negative experiences to people with dementia, carers, and HCPs. Trying to minimize these negative experiences, HCPs often avoid direct terms like “dementia” and “Alzheimer's disease” and are hesitant to provide full details of the diagnosis and its implications. The presence of family or companions is common, and they are considered essential to help communicate the diagnosis to the person with dementia and retain information of the diagnosis. However, despite their presence the disclosure often leaves both the person with dementia and their families feel uncertain about the prognosis and future care.

Due to the natural progression of dementia, people affected can gradually lose their ability to

make decisions at the later stages, especially major medical decisions for life-prolonging treatments, such as hospitalization, cardiopulmonary resuscitation, and artificial nutrition and hydration. People who have recently received the diagnosis of dementia should be informed about common possible problems resulting from dementia and encouraged to make advance decisions for these (Donnelly *et al.*, 2019; van der Steen *et al.*, 2014). Based on the 2005 UK Mental Capacity Act, this needs the person to understand, retain and weigh up information, and communicate their decisions. Having a diagnosis of dementia does not always equate to a lack of capacity to make decisions (Wendrich-van Dael *et al.*, 2020). Decisional capacity itself is neither static nor global in its scope: the diminished capacity for a particular decision should not be assumed or compromise the person's ability in other decisions (Hegde and Ellajosyula, 2016).

Despite the expected declining decisional capacity at the later stages, it is not uncommon that people with dementia are excluded from the discussions too early, including at the diagnosis disclosure sessions (Karnieli-Miller *et al.*, 2012; Yates *et al.*, 2021; Donnelly *et al.*, 2019). Some families would prefer HCPs not to discuss the diagnosis and advance care decisions directly with the patients; conversely, they would like to be informed if they are the persons with dementia themselves, similar to HCP's attitudes (van den Dungen *et al.*, 2014). Some people with dementia may be involved in the decisions at the times, but this can be merely tokenistic, and the actual decision-making is taken behind the scenes by others (Donnelly *et al.*, 2019). HCPs can anticipate these difficult decisions and be clear upfront about the possible decisional capacity lost to the patients and their family. However, this is challenging due to the individual and unpredictable nature of dementia, and people with dementia can feel unsure when making decisions about future situations (Harrison Dening *et al.*, 2016; Bailey *et al.*, 2019). Many health and social care decisions are often left undiscussed and put the responsibilities on to family carers and HCPs to make the decisions at the times of health and social care crises, usually occurring in acute hospital settings (Dickinson *et al.*, 2013; Lamahewa *et al.*, 2018). The urgency of decision-making can be

stressful for the surrogate decision-makers, cloud their judgment, and sometimes lead to overused medical treatments, resulting in the poor quality of life of people with dementia, especially at the end of life (Anantapong *et al.*, 2020; Harrison Dening *et al.*, 2016; Lamahewa *et al.*, 2018).

Most guidelines have promoted the diagnosis disclosure but usually not specified or discussed circumstances in which the diagnosis is not shared with the person living with dementia themselves, requiring HCPs to use their clinical judgment (Carpenter and Dave, 2004). HCPs are sometimes reluctant to disclose the diagnosis and discuss a care plan with people with dementia, even sometimes with their family members or companions. This can be because they feel pessimistic about dementia trajectory and limited curative treatments and worry about upsetting patients and families (van den Dungen *et al.*, 2014; Yates *et al.*, 2021). Some HCPs also acknowledged that social and health care resources would be scarce in their community: some might simply not know about their available resources (Bradford *et al.*, 2009). Some HCPs do not feel confident in their skills to engage in difficult discussions, and they cannot easily apply learnings from the general breaking bad news framework (Bailey *et al.*, 2019). Different cultural and social perceptions around dementia symptoms make it even more challenging for HCPs when disclosing the diagnosis to the person with dementia and their family with different background (Cipriani and Borin, 2015). Yates *et al.* (2021) found some HCPs might prefer using euphemisms, but all HCPs in some recent studies used direct terms like “dementia” in diagnostic disclosure (Bailey *et al.*, 2019; Dooley *et al.*, 2018). This would suggest cultural shift in practice that tends to be more open, although those who use clear diagnostic terms still downplay when discussing prognosis and available treatments (Dooley *et al.*, 2018).

Many family members find that the diagnosis disclosure is a positive experience to be confirmed and relieved of their anxiety over the patients’ symptoms (Werner *et al.*, 2013; Yates *et al.*, 2021), but they may start to recognize their changing role and growing responsibility as a carer (Karnieli-Miller *et al.*, 2012). Although some people with dementia can experience short-term negative or catastrophic reactions from the diagnosis disclosure, they want to be involved in the conversations to know what happens to them and what they can do for their future (Yates *et al.*, 2021). This could give them a sense of hope and help them through their diagnosis, developing a plan to live well with dementia; however, this still needs to be realistic.

An advance care plan (ACP) is a process to facilitate a person with dementia and their carer

together with HCPs to discuss goals and preferences for current and future care in anticipation of future deterioration or reduced decisional capacity of the person (Wendrich-van Dael *et al.*, 2020). ACP gives the patients every opportunity to retain control of their life, while they have the capacity to do so (Shelton *et al.*, 2018). ACP can help patients receiving treatments aligned to their wishes and reduces the overuse of medical treatment at the end of life (Silveira *et al.*, 2010). ACP also helps enhance carer confidence and reduce their decisional conflict when making difficult decisions, and also increases carer satisfaction with the care for people with dementia (Wendrich-van Dael *et al.*, 2020). However, ACP cannot always specify enough detail for some common medical decisions as contexts constantly develop and change; this can result in some being reluctant to use them in clinical practice (Anantapong *et al.*, 2020; Vandervoort *et al.*, 2014). Evidence demonstrates that at one to three months after knowing the diagnosis, carers were able to begin organizing themselves and arranging practical help for persons with dementia (Werner *et al.*, 2013). However, lack of understanding of the life-limiting nature of dementia, delayed diagnosis, confusion about their roles, preference to informal care planning, and difficulty in finding the right time among all involved could hinder or delay the discussions of ACP (Dickinson *et al.*, 2013; Bradford *et al.*, 2009). HCPs should sensitively assess the receptiveness of the patients and carers to the discussion and are recommended to have follow-up sessions to establish the ACP once the patients and carers seem intellectually and emotionally prepared (Shelton *et al.*, 2018; Yates *et al.*, 2021). Good documentation and regular updates of the existing ACP are also important to ensure that the person’s wishes and preferences are heard and respected.

In conclusion, it has been recommended that people with dementia and their carers should be informed about future decision-making problems and offer early discussions around ACP (van der Steen *et al.*, 2014), but we still know less about how we can do this properly. Yates *et al.* (2021) found that the diagnosis disclosure still usually offered only basic information, and people with dementia and their carers felt they lacked information about future and prognosis, sources of support, and local health and social services. It needs public openness and funding to increase time resources and staff competency to have ongoing conversations around care plan during the diagnosis disclosure sessions. Decisional support to help those who have missed the opportunity to involve the person with dementia in advance decision-making and developing ACP is also important.

Conflict of interest

None.

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