17th of September, 2020

Dear Dr William Breitbart and the editorial board of Palliative & Supportive Care,

We would like to submit our manuscript “Discordance between the perceptions of clinicians and families about end-of-life trajectories in hospitalised dementia patients” for consideration of publication in your journal.

There is a compelling argument that end-of-life admissions to hospital are undesirable for people with dementia, and that ideally end-of-life care provided in home or residential care settings. This mitigates the risk of invasive or aggressive treatments used for investigation of life-limiting events and potential futile treatment. This rests on the assumption that dementia should be approached through a palliative care philosophy, with treatment goals that augment comfort. Yet, identification of a ‘palliative phase’ in the dementia trajectory is challenging and, in reality, patients with dementia often receive palliative and end-of-life care in hospital settings following admission due to unpredictable events.

We were interested in examining how clinicians and families conceptualised dementia as a life-limiting condition and how this knowledge informed awareness and understanding of terminal outcomes for patients with dementia in hospital. Using a qualitative design, we interviewed 32 participants to gain insight into how traditional disease trajectories models inform clinical care. Our findings highlight the discordance between clinicians’ views and families’ experiences in relation to end-of-life admission for people with dementia, both in relation to broad perceptions of dementia as a life-limiting condition as well as terminal trajectories during an acute admission. Our findings address a gap in knowledge that has clinical implications regarding palliative and end-of-life care for patients with dementia in hospital. Furthermore, we respectfully challenge the clinical benefit of traditional illness models in the hospital context.

Kind regards,

Felicity Moon, David W. Kissane and Fiona McDermott.