




## COMMENTARY

# The swinging pendulum of risk management: is it time to reimagine risk in dementia care?

Commentary on “Risk assessment for people living with dementia: A systematic review” by Hoe *et al.*

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## Introduction

Enacting the principle of *primum non nocere* or “first do no harm” can often feel like a challenging endeavor when supporting people living with dementia (PLwD). How do we prevent foreseeable risks without causing harm in the process? Perhaps the risk pendulum has swung too far, resulting in excessive harm to mitigate risk. Various forces pull this pendulum in opposing directions, and finding the optimal equilibrium point in clinical practice is difficult. Consider the clinical example of a person who is at high risk of aspiration due to dysphagia in the context of dementia. An aspiration pneumonia can be prevented through the restriction of certain food or fluid textures, but this can come at the expense of significantly reduced quality of life; for example, missing out on the joy of their favorite chocolate that they have eaten for sixty years of their life. Along similar lines, a recent societal challenge was trying to achieve the difficult balance between COVID-19 restrictions that were intended to protect the population, and the potential harms of social isolation (Chong *et al.*, 2020).

These confronting and challenging clinical scenarios are likely to be encountered with a greater frequency over time, given rising global prevalence rates of dementia. The global prevalence of PLwD is estimated to increase to nearly 153 million by 2050, compared with an estimated 57 million in 2019 (Nichols *et al.*, 2022). This is of significant concern, given the high rates of morbidity and mortality associated with the diagnosis. As a result, there has also been increasing attention given to dementia risk reduction or prevention (Chong *et al.*, 2021).

When compared with people without a diagnosis of dementia, PLwD have a higher rate of falls, accidents, accidental poisoning, accidental death, fractures, wandering, and increased mortality (Agrawal *et al.*, 2021; An *et al.*, 2019; Piovezan *et al.*, 2020). Substitute decision-makers and health practitioners may attempt to minimize these risks by making specific environmental modifications, potentially at the expense of reduced patient autonomy. Examples include the removal of car keys to prevent motor vehicle accidents, cooking with a microwave rather than a stove to minimize the risk of housefires, and implementation of medication supervision to prevent accidental overdoses.

Various legal frameworks exist globally to help address the risk issues associated with PLwD in the event of diminished decision-making capacity. These allow substitute decision-makers (such as carers or next-of-kin) the ability to provide oversight of a person's care and treatment. When examining the context in the state of Victoria, Australia, the Guardianship and Administration Act 2019 allows for the appointment of a substitute decision-maker to support people with diminished decision-making capacity, including those with dementia. It is encouraging that there has seemingly been a cultural shift, as reflected explicitly in the stated intentions of the Act. The Act aims to shift away from a “paternalistic approach to disability to a position of promoting the dignity, equality and autonomy of people living with disability, while retaining the safeguards necessary for them to most fully realise their potential” (OPA, 2023).

In light of this context, the systematic review by Hoe *et al.* (2023) is very timely. Their review focused on risk assessment in people with dementia, which is

a highly relevant and important issue facing clinicians, PLwD, and their families and carers. This includes key components of risk assessment, attitudes of PLwD toward risk, and the usefulness of available tools. These aims are all of interest to clinicians working with PLwD, families, and carers.

The review methodology is clearly defined, the review was preregistered and followed PRISMA guidelines, and the search strategy and selected databases, including grey literature, were comprehensive (Hoe *et al.*, 2023). Twenty studies met criteria for inclusion in the review, and most were from developed nations. Triangulation was a key strength of the methodology in this review. One of the main findings was that PLwD were more risk-tolerant compared to healthcare professionals who were more risk-averse. Falling and getting lost was the most frequently identified risk concern while disruptions to routines and settings, medication management, and unclear care pathways were found to increase risk. Disappointingly, there was no risk instrument identified in the review that was shown to be useful, and this reinforces the need for more research attention in this field (Hoe *et al.*, 2023).

Of note, the concept of positive risk management or risk enablement is a very promising development. “Risk enablement” is defined by Hoe *et al.* (2023) as “balancing the rights of the PLwD to retain as much control as possible, with those of society and families’ wishes to reduce risks and promote safety at home.” All of these considerations play a key role in supporting PLwD to “live well at home for as long as possible” (Hoe *et al.*, 2023). We would add the concern of clinicians and health services to this balancing act, and we feel that there are sometimes inexorable forces pushing the pendulum to swing toward protecting from risk and harm, potentially at the expense of autonomy and quality of life.

Hoe *et al.* (2023) clearly highlight this tension between risk aversion, primarily from the perspective of clinicians, and risk tolerance advocated for by PLwD. Indeed, there is a broader movement in society to reconceptualize risk-taking away from an exclusively negative concept, toward acknowledgment of positive outcomes. This is evidenced in Australia by the Guardianship and Administration Act 2019 mentioned above (OPA, 2023), as well as the Victorian Mental Health and Wellbeing Act 2022, which incorporates “dignity of risk” as a core principle (Victoria, 2022). By doing so, the importance of respecting an individual’s right to take risk is acknowledged at a legislative level in the state of Victoria, Australia. However, the next question that arises is how can clinicians, on an individual level, be best supported to hold the greater level of uncertainty inherent to risk enablement?

Risk assessment scales are a key tool used in identifying and quantifying risk and guide clinicians about when to intervene. Despite this, their usefulness is limited when it comes to predicting rare outcomes such as suicides (Runeson *et al.*, 2017). Whilst some adverse events for PLwD are more frequent, for example falls (Agrawal *et al.*, 2021), Hoe *et al.* (2023) have still highlighted that there are no widely acceptable and useful assessment scales available to guide risk management in this area. What is more, only one risk assessment scale included a question about insight, despite reduced awareness amongst PLwD being associated with greater exposure to dangerous behaviors (Fischer *et al.*, 2023). The significance of insight on outcomes for PLwD has led to recent efforts to better understand factors that mediate it. For example, Fischer *et al.* (2023) investigated the relationship between cognitive function, mood, and functionality on awareness in 264 people with Alzheimer’s disease aged 60 years and older. This study identified that functionality, rather than cognitive level or depressive mood state, may have a direct effect on awareness (Fischer *et al.*, 2023). Thus, inclusion of insight into future risk assessment scales may hold clinical utility.

Risk assessment scales, however, will not be the only solution if we hope to advance toward risk enablement. The perspectives of PLwD and their families and carers will be pivotal in advocating for change, and the work of Hoe *et al.* (2023) is valuable for this reason. We strongly agree with the recommendation to make PLwD central to decision-making (Hoe *et al.*, 2023). A key consideration is that this can become more difficult over time, given the increased likelihood of anosognosia as the condition progresses, impairing the capacity, insight, and the ability of some PLwD to fully understand the risks being considered (Starkstein, 2014). Clinicians may be emboldened to hold more uncertainty with increased access to legally documented preferences declared when an individual has capacity. Yet in one study, more than half of persons with dementia did not have an advance care directive (Bryant *et al.*, 2023). This may reflect a lack of knowledge in the wider community regarding dementia, and research has shown that even among people with early cognitive impairment, most were unaware of the decisions they could potentially face and for which they needed to plan (Fried *et al.*, 2021). Thus, greater efforts early on – including among those at high risk of dementia or with mild cognitive impairment – to educate and engage in advance care planning are essential.

Another important consideration in having PLwD central to decision-making is awareness of

the impact of socioeconomic factors. As an example, Giebel *et al.* (2023) conducted a cross-sectional longitudinal cohort study of 15,742 people with Alzheimer's disease dementia in the United States investigating the effect of ethnicity on use of dementia medications. This study found that people from minority ethnic backgrounds used cholinesterase inhibitors and memantine less than those from a White ethnic background (Giebel *et al.*, 2023). It is thus important to consider socioeconomic factors such as ethnicity when considering risk and risk enablement.

In addition to public health policy and legal frameworks, clinicians also operate within organizational risk cultures and are bound by a duty of care. Creating change at this level will require even more concerted efforts and creative thinking, and at present, we still do not have a clear solution for achieving this. Hoe *et al.* (2023) make helpful suggestions around communication pathways, sustaining activities instead of avoidance and individualizing risk assessments. Relating to the latter, clinical staff would benefit from training to incorporate the unique strengths, limitations, and core values of each individual PLwD into risk assessments rather than exclusively relying on "tick-box" scales. The process of risk enablement can also be encouraged through open discussions within a multidisciplinary team, with emphasis on reflection and capacity building in the face of adverse events rather than blame and fear of legal ramifications. Similarly, the inclusion of PLwD, carers, and representative bodies in organizational planning around such change would help place quality of life at the center of any discourse that is perhaps vulnerable to being skewed by competing interests, including financial and legal.

Our aspiration is to work alongside PLwD and their loved ones to reimagine risk within the context of dementia. We must collaborate to pull the risk pendulum back to the optimal equilibrium point through risk enablement, with the ultimate aim of improving quality of life.

### Conflicts of interest

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All the authors contributed to writing the paper.

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