

A person-centred approach to decision-making and care for persons living with dementia

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ABSTRACT

Global population ageing will increase the prevalence of cognitive impairment and dementia. Persons living with dementia (PLWDs) often face complex care and medical needs that entail carefully considered decisions. The current framework for decision-making prioritises mental capacity, personal autonomy and best interests. PLWDs are assessed on whether they possess the mental capacity to make informed decisions and if not, healthcare professionals (HCPs) will act in their best interests. However, as decision-making capability exists in a continuum and varies depending on the complexity of the health issue, there may be subjectivity among physicians in categorising PLWDs into those with or without mental capacity, especially in borderline cases. Furthermore, such a binary and reductive approach may not secure the best outcomes if conducted in a legalistic manner. PLWDs deemed to possess mental capacity are allowed to make decisions that may be detrimental to themselves while those assessed to lack mental capacity have unwelcome decisions imposed upon them. This paper proposes a person-centred framework that promotes relational autonomy so as to enable PLWDs to express their values and preferences in a manner that serves them best. The framework is a convenient guide in helping HCPs enable PLWDs to have a better hold on to their personhood and agency, and balance the demands of upholding autonomy with best interests.

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INTRODUCTION

Assessing mental capacity in persons living with dementia (PLWDs) in high-stakes decision-making is becoming more frequent amid an ageing population with a rising prevalence of cognitive impairment and dementia. A study estimated that the population of PLWDs globally will almost triple by 2050.¹

Among the 4 ethical principles—autonomy, beneficence, non-maleficence and justice—the primacy of autonomy² draws from John Stuart Mill's perspective that individual rights should only be infringed to prevent harm to others and is underpinned by the presumption of agency—that individuals make decisions based on their free will.³

However, agency presupposes mental capacity. It is noteworthy that the 4-step mental capacity test (understanding, recalling, weighing and communicating) is liable to examiner bias and inter-observer subjectivity in borderline cases.⁴ Furthermore, autonomy may conflict with the other ethical principles, for instance, non-maleficence, which seeks to do no harm, and beneficence, which is to do good. Examples include a patient who refuses a beneficial treatment plan, or wants a potentially harmful discharge against medical advice. The following scenario below depicts the tension in balancing PLWD's agency with beneficence.

Case scenario

Mr. Edward, who has mild dementia, diabetes mellitus, knee osteoarthritis with gait instability and end-stage renal failure on dialysis, was admitted for a head injury post-fall and pneumonia. Prior to admission, he lived alone but could navigate his neighbourhood and handle simple finances. His sister, who visited him monthly, helped to coordinate his medical appointments but was busy with a full-time job. During his hospital stay, he displayed bouts of emotional outbursts, refusing medications and on occasions, rejected dialysis. Although he appreciated the risks of staying alone given his recurrent falls and declining health, he stated he "values his freedom over everything else". He was unable to elaborate how he would cope at home and mitigate the risks. When confronted with a life-threatening event alone at home, he became teary, and said he "entrusted all to God" and believed he would be "protected from harm".

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Challenges in the case scenario

Determining what is best for Mr. Edward entails finding the balance between upholding his agency and preferences, and safeguarding beneficence and non-maleficence. His desire to live alone poses hazards to his well-being, but overriding his wishes should he be deemed to lack of mental capacity risks consigning him to institutional care against his will.

Furthermore, there is ambiguity regarding Mr. Edwards' capacity. Although he demonstrates some ability to appreciate the consequences of the choices at hand and weigh the situation, he resorts to leaps of logic, becomes emotional and espouses magical thinking. Such thinking may also be influenced by personal, cultural and spiritual beliefs, which may be challenging for external parties to fully appreciate.

As Appelbaum and Grisso acknowledge, "the evaluation of competence does not...lead to unambiguous ratings of 'no ability' or 'full ability' on all dimensions. On the spectrum of functional impairment, most patients fall somewhere in the middle".³ Unfortunately, the current medical-legal framework adopted in the UK and many Commonwealth countries conflates these complex assessments into capacity/incapacity binaries, leaving physicians with limited room to manoeuvre within these ambiguities.⁵

A proposed person-centred framework

Our approach is based on person-centred care (PCC) (Fig. 1) to better operationalise the principles of patient autonomy and beneficence in decision-making for PLWDs. PCC, per the American Geriatric Society, involves eliciting "'individuals' values and preferences...supporting their realistic health and life goals...informing decision-making to the extent that the individual desires."⁶ This involves a departure from hyper-cognitivism and hence mental competence to recognising the intrinsic value of and common equality among persons. It also draws on a more expansive understanding of personhood based on enhancing relational autonomy.

Even as PLWDs lack advanced cognitive capabilities, they still possess inalienable interests, including the capacity for sadness, suffering and a "sensitivity to the behaviour" of those around them,⁷ and therefore deserve the right to be respected, taken seriously and be themselves.⁸ Autonomy should be broadened to social and relational roles, to better encapsulate individual nuances and support the exercise of agency in PLWDs.

The proposed approach involves appreciating the PLWD's prior preferences, values and beliefs, as well as the severity of cognitive impairment. Thereafter, ways to facilitate agency can be explored. It would entail managing ambivalence, promoting relational autonomy to support the preferences of PLWDs and enabling dyadic communication.

(1) Managing ambivalence

Mr. Edward demonstrates ambivalence in his care options: he wishes to return home and continue independent living yet refuses to stay in the hospital to receive the necessary treatment and rehabilitation to achieve it.

Navigating ambivalence requires identifying the underlying mental state, namely, whether patient is avoiding conflict, indecisive, displaying mood fluctuations, apathetic or whether he is truly ambivalent.⁹ For Mr. Edward, he has conflicting preferences: refusing to be hospitalised longer even though he appreciates his need for treatment. Prolonged hospitalisation has also increased his frustration and fuelled his low mood and agitation, heightening his impulse to go home without regard of the consequences.

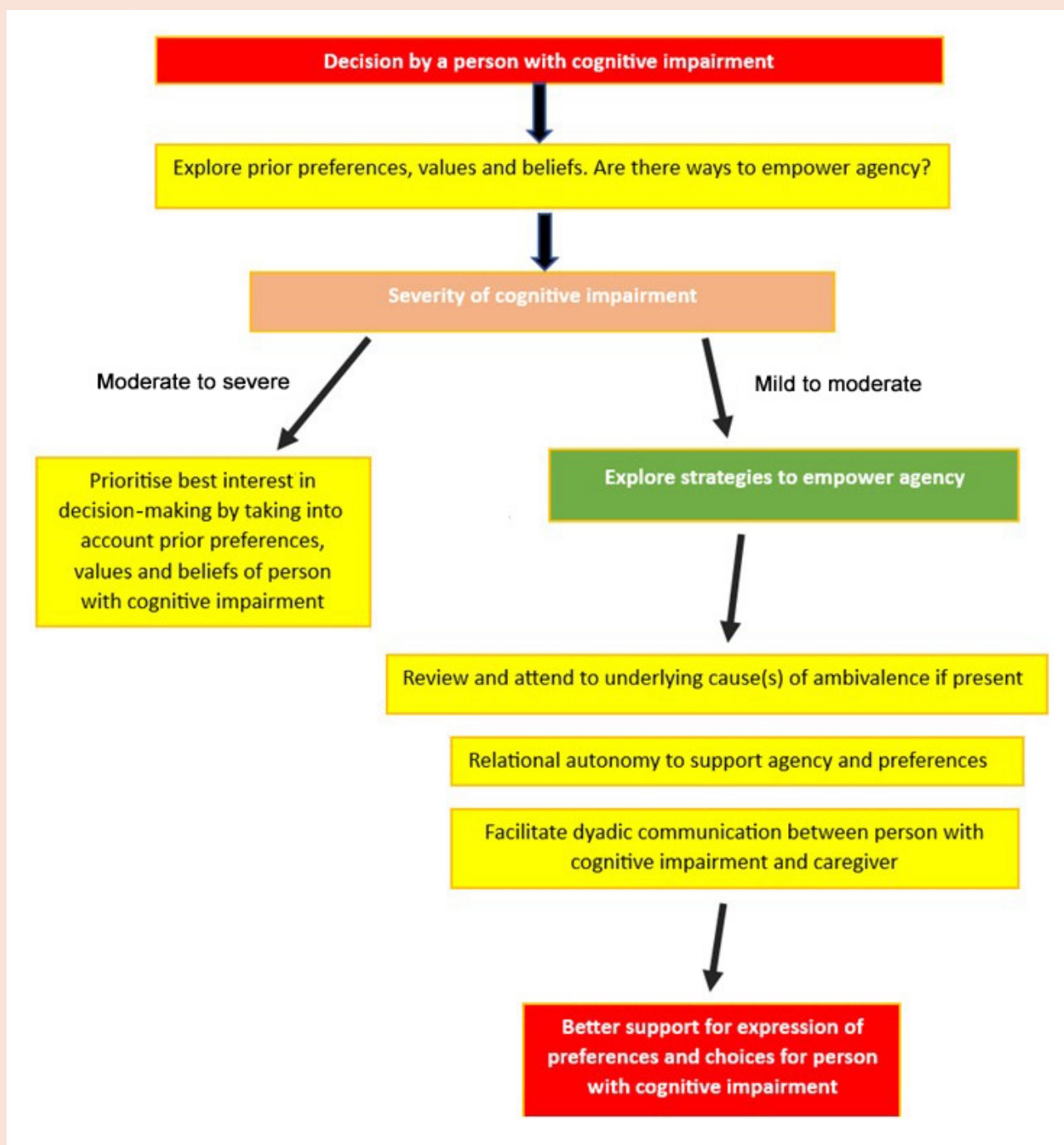
Managing ambivalence involves reviewing whether the label of "ambivalence" is secondary to any miscommunication or misunderstanding.¹⁰ If there is genuine ambivalence, strategies include discussing the consequences of the decisions, allowing space and time to come to an optimal decision, avoiding undue pressure to make a premature decision and not labelling patients as difficult.⁹ It might be useful to consider a short duration of home leave to satisfy Mr. Edward's desire to go home, which could provide greater clarity on whether he can continue to live on his own with the necessary home assistance and support put in place.

(2) Relational autonomy to promote agency and preferences

HCPs and caregivers can draw on relational autonomy to enable agency in PLWDs. Relational autonomy recognises that agency may be undermined in vulnerable populations by societal structures, norms and expectations.¹¹ It argues that self-determination requires access to significant social goods and opportunities to make meaningful choices.¹²

For Mr. Edward, a relational autonomy model recognises that social structures can help or hinder him from expressing his preferences, such as lacking a dedicated caregiver and transportation to and from dialysis. His inability to self-govern

Fig. 1. Proposed model of person-centred decision-making for persons living with dementia.



is contributed by the lack of familial relationships and community assistance to support his choices. Conversely, PLWDs with strong familial or social support are better able to express their autonomy and live according to their preferences. Improved home-based care services can better support PLWDs to age-in-place, while policies such as transport arrangements and subsidies for home medical services can allow PLWDs to better access healthcare without institutionalisation.

Therefore, supporting PLWDs' agency entails allowing them to exercise their personal preferences in day-to-day living, empowering them through dyadic relationships with close caregivers, and tailoring the approach according to severity of the cognitive impairment. PLWDs can hold on to longstanding values, beliefs and preferences that direct their healthcare and lifestyle choices,¹³ and through this, express their agency.¹⁴ Familial caregivers familiar with the person's personality and

biography can help identify long-standing preferences and beliefs, to enable preference-based care.¹⁵

Preference-based care respects PLWDs' preferences as a reflection of their values, biographies and personalities, and adjusts the physical and social environment to meet these needs. Some examples to assess preferences include the Preference for Everyday Living inventory, which includes aspects such as hobbies, social interactions, personal grooming, caregiving choices and healthcare behaviour of persons with cognitive impairments.¹⁶ However, these standardised tools may not specifically target the Asian population given the unique sociocultural context.

(3) Promoting dyadic communication

Caregivers, often familial ones, can journey with PLWDs as dyads. In the Asian context, with strong emphasis on filial piety and familial relationships, these family members form repositories of memory, cueing the person to important anniversaries, milestones and events, as well as routines and rituals to support the exercise of their agency.¹⁷ Other forms of collaboration include developing new means of communication, for instance, through body language or code words for persons stricken with aphasia, or providing navigation for those with visuo-spatial impairments. Close kin and friends will also be familiar with and thus able to respect and support the expression of religious and spiritual beliefs of the PLWD. If there are no close kin or neighbours to assist, the PLWD can turn to befriender or volunteer services.

In this way, caregivers help PLWDs retain personhood by maintaining a coherent biography and value structure, through the "telling, retelling and checking of stories out of which identity is built".¹⁸ For Mr. Edward, a potential dyad is his sister, with whom he shares a close relationship. She is already performing roles to help support his independence in the community by scheduling his medical appointments and can step up further as he inevitably declines to fulfil his preference of ageing-in-place at home.

However, care must be taken to prevent paternalism, where the caregiver dominates the relationship, oversteps boundaries and takes over roles that the PLWD can still perform. For example, caregivers should seek permission from the PLWD before assisting in custodial care activities such as bathing; and when that is no longer feasible, to provide a request, explanation and expression of concern in respect for personhood.⁸

Tailoring the framework to the severity of dementia

Even a limited level of agency is challenging for persons with advanced cognitive impairment, such as patients with severe dysphasia or who are very disoriented and out-of-touch with reality. HCPs, however, must be mindful to support non-verbal or alternative forms of agency such as body language and facial expression, in appreciating the PLWD's intentions and preferences, and not "conflate" "language with rationality".¹⁹ In addition, for PLWDs with more severe cognitive impairment, caregivers can be more mindful of prior preferences, values and beliefs. In contrast, for PLWDs with milder cognitive deficits, strategies should draw more on relational autonomy and dyadic communication.

CONCLUSION

In "Holding one another in a time of dementia", Lindemann, writing a narrative about a family's interaction with a grandmother in the thralls of dementia, shows that through small acts of caring or holding, families can construct and rebuild narratives that allow PLWDs to demonstrate moral agency and what they value.²⁰ Such agency can have significant meaning for PLWDs and their caregivers, allowing them to express their intrinsic humanity, dignity and value.

A more expansive person-centred model based on agency and relational autonomy can help PLWDs negotiate complex care and medical decisions in a manner consistent with their personal values and preferences, by upholding their personhood and identity, while protecting their best interests. Such a model also dovetails with Asian values emphasising communitarian, collectivist and family-oriented values, which can be facilitated by relational autonomy and dyadic communication.

Ethics statement

Not applicable.

Declaration

The authors declare they have no affiliations or financial involvement with any commercial organisation with a direct financial interest in the subject or materials discussed in the manuscript.

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