Upholding personhood in dementia palliative care

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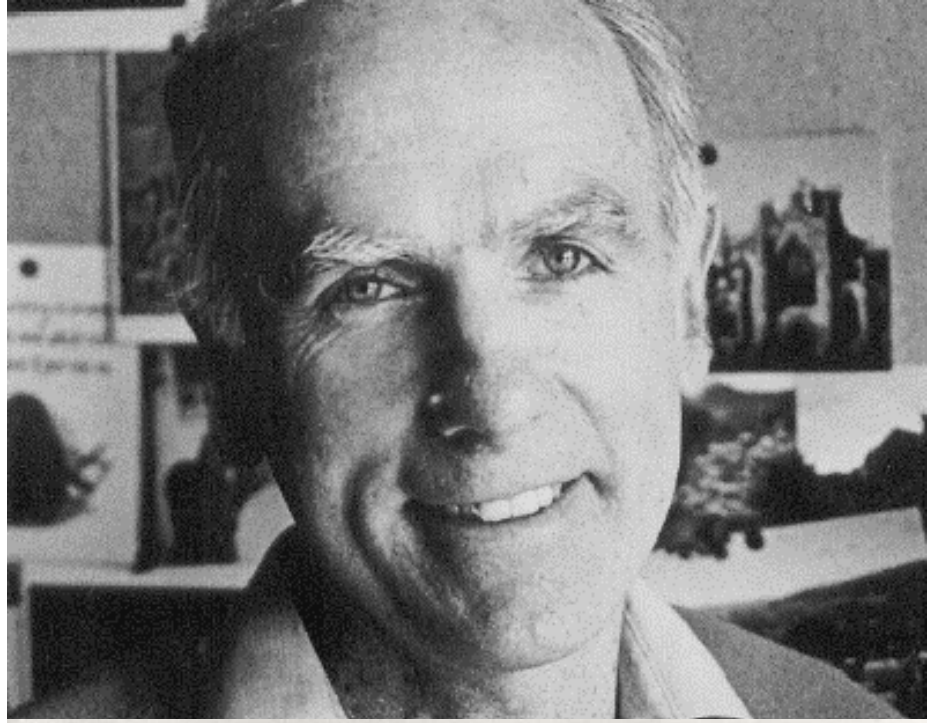
Personhood means recognising the person beyond the disease—valuing their identity, relationships, history, preferences, and dignity at every stage of care (Kitwood).

You matter because you are you, and you matter to the last moment of your life (Saunders).



Recognition of dementia as a terminal condition (2000s)

Evidence:

- Advanced dementia has high mortality
- Comparable to other life-limiting illnesses

Shift towards:

- Early identification of decline
- Advance Care Planning (ACP)

Development of:

- Prognostic tools (e.g., FAST)
- Early palliative triggers

Integration between dementia care and palliative care

Dementia care is palliative care

- It is a specialised palliative approach due to the disease's complexity
- It has to be person-centered and relationship based
- Requires Advance Care Planning and knowing the person to ensure preferences are known
- There is a focus on quality of life, on living well with dementia, managing symptoms and maintaining connections

Kitwood – six psychological needs – essential to all people

- Love: unconditional acceptance and empathy.
- Comfort: the person needs security, warmth and proximity.
- Identity: is connected to know who one is and has a connection with the past.
- Affiliation: linking ties, relationships with others. To experience confidence and trust in the relationship, so that you have someone to go to in difficult situations.
- Meaningful employment: to participate in your own life in such a way that you use your abilities, strength, and experience. That you are needed and that you have something to do.
- Inclusion: Being part of a social community and feeling accepted.

- Addressing negative social psychology

Personhood linked to Person–centred care

- Focused on the persons perspective and experiences
- Quality of life, optimize maintenance of function and maximization of comfort
- ACP equity in access, inclusive approaches and conversations to express the persons' values
- Knowing the person's life history
- Using reminiscence and storytelling
- Interpreting behaviour in context
- What's important to the person 'Know me' 'This is me" 'my day my way'
- What would a good day look like
- Selfhood
- Meaningful connection
- Communicating when the person is in FAST 6/7
- Meeting the person where they are
- Domains of palliative of care applied (physical, psychological, social and spiritual)
- Sensory meaning
- Bereavement support is provided before and after death, families/carers may need early and ongoing support for chronic or prolonged grief.

Person-centred dementia care VIPS Framework (Very Important PersonS)

(Brooker 2006)

V – Value

Value people with dementia and their carers

Promote dignity, rights, and inclusion

Regardless of age or cognitive ability

I – Individualised care

Every person is unique

Consider life history, personality, health, and resources

Tailor care to the individual

P – Perspective

See the world through the person's eyes

Their experience is meaningful and valid

Empathy has therapeutic value

S – Social environment

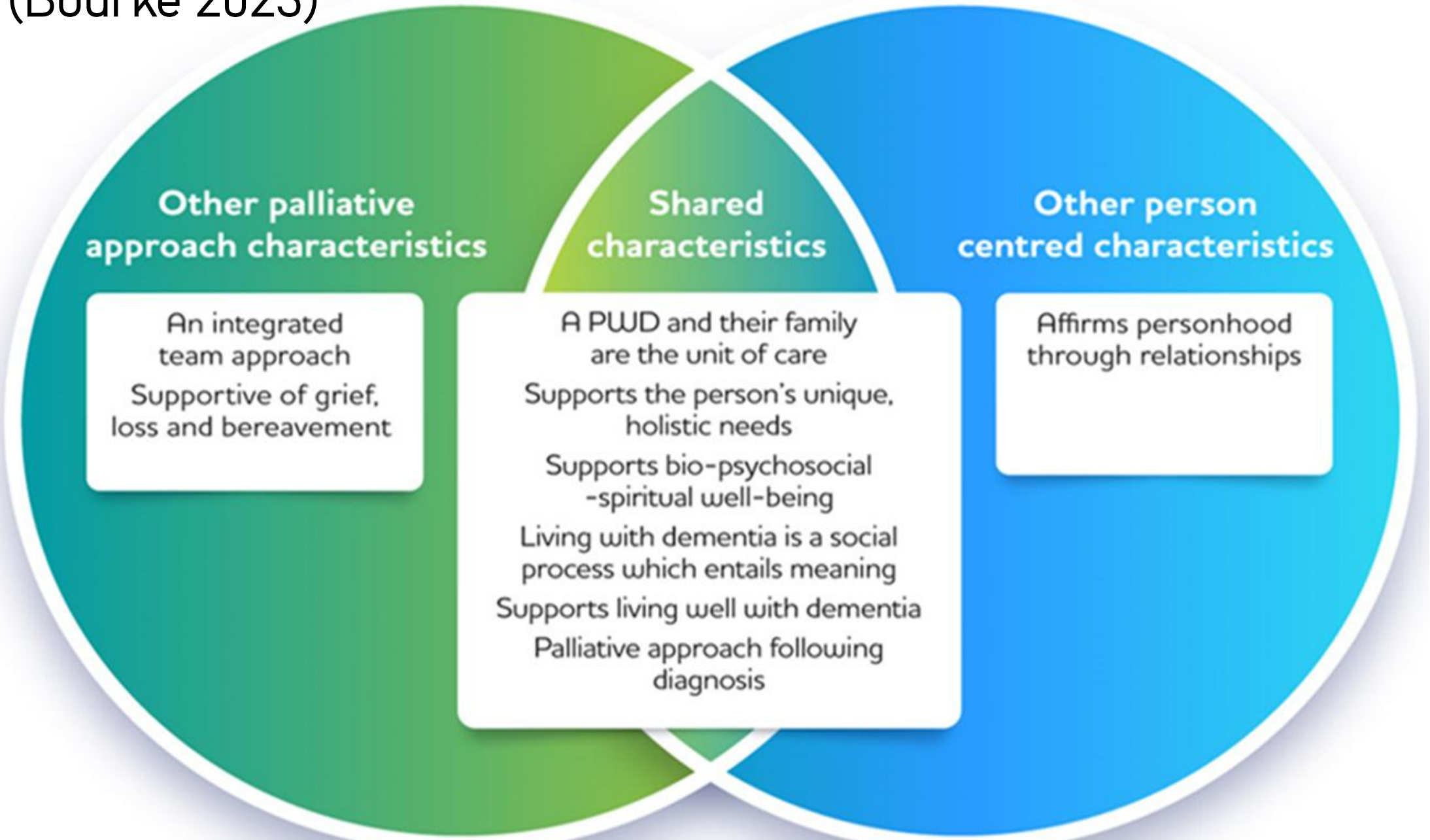
Care is grounded in relationships

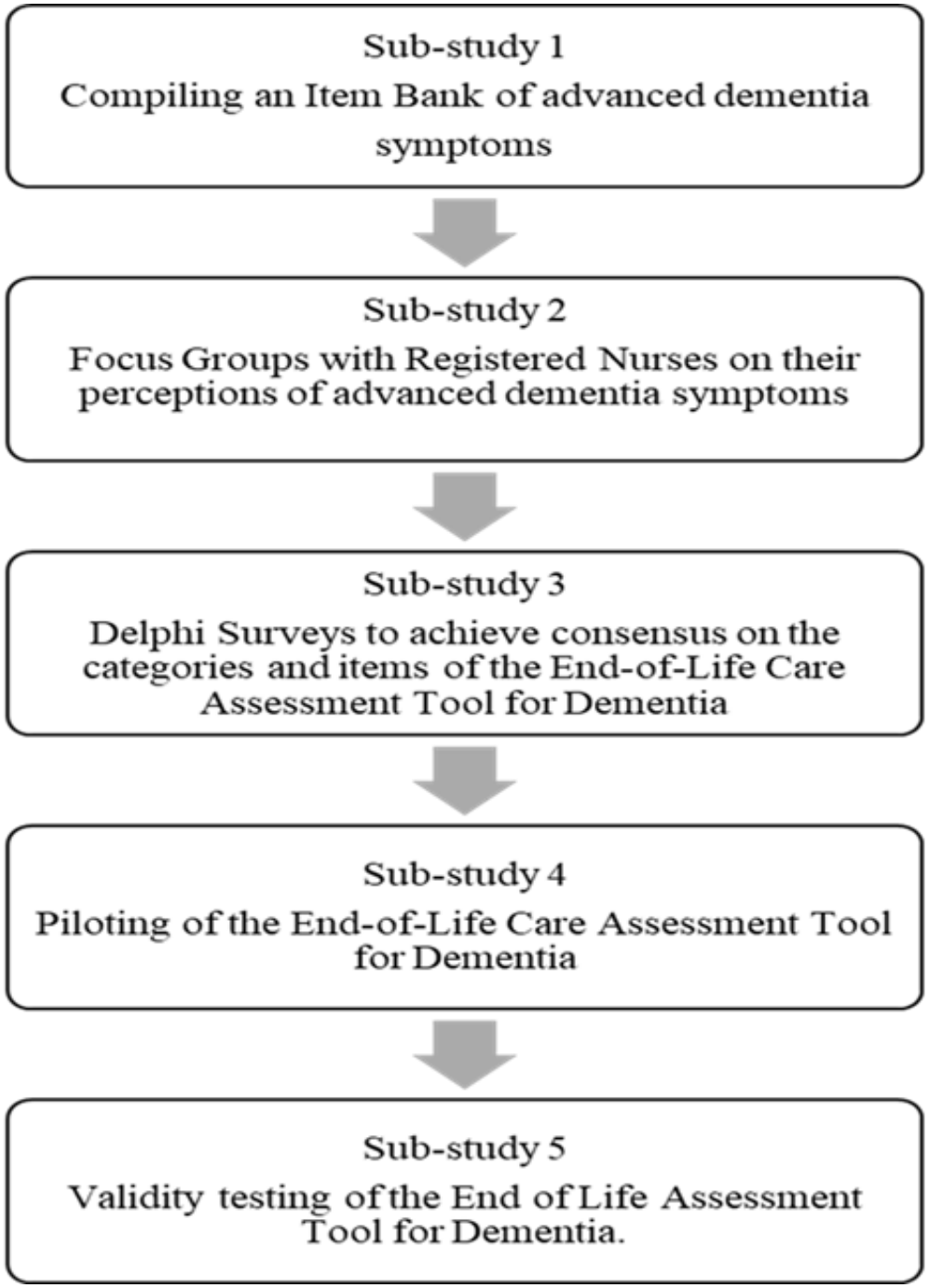
Support connection, belonging, and comfort

Create an environment that enables wellbeing

(Care Fit for VIPS. The VIPS Framework. 2025)

Putting the Person at the Centre of End-of-Life Care (Bourke 2023)





Creating a reliable way to Assess End-of-Life Care in Advanced Dementia 2018-2024

- My study aim was to develop the End-of-Life Assessment Tool for Advanced Dementia

- Helping nurses recognise need, act early, and deliver better palliative care.

End of Life Care Assessment Tool for Dementia (EoLC-ATD)

Consider signs and symptoms present over the *past 7 days*
Allocate a NO if following signs and symptoms are not currently present
Allocate a YES if the following signs and symptoms are currently present

	1 Cognition (conscious mental processes that occur in the process of thinking, including identification, understanding and perception of knowledge)	Yes	No
1	1a Unable to focus/pay attention		
2	1b Unable to retain new information		
3	1c Confusion (place and person)		
	2 Personhood (sense of self, autonomy & self-determination in expressing choices and decisions)		
4	2a Unable to express personhood (e.g. unable to engage in a meaningful way, either verbally or facially)		
5	2b Does not indicate their own preferences for care		
6	2c Does not engage in decisions regarding whether or not to take medications (e.g. not able to ask for pain relief; not able to refuse medication verbally or through behaviour)		
7	2d Does not engage in decisions about treatment for a medical condition (e.g. unable to respond when BP, or BGL are undertaken)		
8	2e Does not indicate the need to eat or drink		
	3 Behaviour (responsiveness, the way in which one acts or conducts oneself, especially towards others)		
9	3a Apathetic (appears not engaged most of the time)		
10	3b Agitation (e.g. frequent requests for attention or calling out, pacing, repetitive actions such as fidgeting and plucking)		
11	3c Resistance to care (e.g. physically and/or psychologically resisting, pulling away, tightening limbs, stiffening, waving arms and legs and verbally objecting to care with words and/or sounds)		
	4 Function (ability to perform basic and instrumental activities of daily living)		
12	4a Unable to self-feed		
13	4b Unable to attend to personal hygiene		
14	4c Unable to dress completely and in the right way		
15	4d Unable to self-toilet without full assistance, unrelated to physical disability		
16	4e Incontinent of urine		
17	4f Incontinent of faeces		
18	4g Bedfast, chair-fast		
	5 Physiological state (mechanical, physical, and biochemical function)		
19	5a Significant weight loss unrelated to physical illness (BMI <18.5 kg/m2)		
20	5b Altered appetite and/or decreased food intake (eating less than ½ the meal)		
21	5c Difficulty chewing		
22	5d Choking on food and fluids		
23	5e Altered thirst and decreased fluid intake		
24	5f Pressure injury (stages 1-6) or skin integrity high risk (Waterlow >15)		
	6 Psychological state (state of mind including emotions/mood/suffering)		
25	6a Anguish (e.g. pain, grief or fear)		
26	6b Anxiety		
	7 Other symptoms (Please describe in free text)		
27	7a		
	YES, total score (for signs and symptoms are currently present)	/27	

The End-of-Life Care Assessment Tool for Dementia (EoLC-ATD)

- This tool is a validated measure that screens for symptoms occurring in moderate to advanced dementia.
- Designed to be used by registered nurses in the aged care setting
- The symptoms identified with the EoLC-ATD assist with planning and monitoring palliative and/or end-of-life care that supports the unique symptoms occurring for the person living with dementia.
- A free tool, it requires minimum training and takes 10-15 minutes to administer - following discussion with direct care staff and others able to contribute advice on the person's symptoms over the past 7 days
- And a review of the person's other clinical assessments and broader psychosocial history

Personhood (sense of self, autonomy & self-determination in expressing choices and decisions)

2a Unable to express personhood (e.g. unable to engage in a meaningful way, either verbally or facially)
2b Does not indicate their own preferences for care
2c Does not engage in decisions regarding whether or not to take medications (e.g. not able to ask for pain relief; not able to refuse medication verbally or through behaviour)
2d Does not engage in decisions about treatment for a medical condition (e.g. unable to respond when BP, or BGL are undertaken)
2e Does not indicate the need to eat or drink

Thank you and Stay connected

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