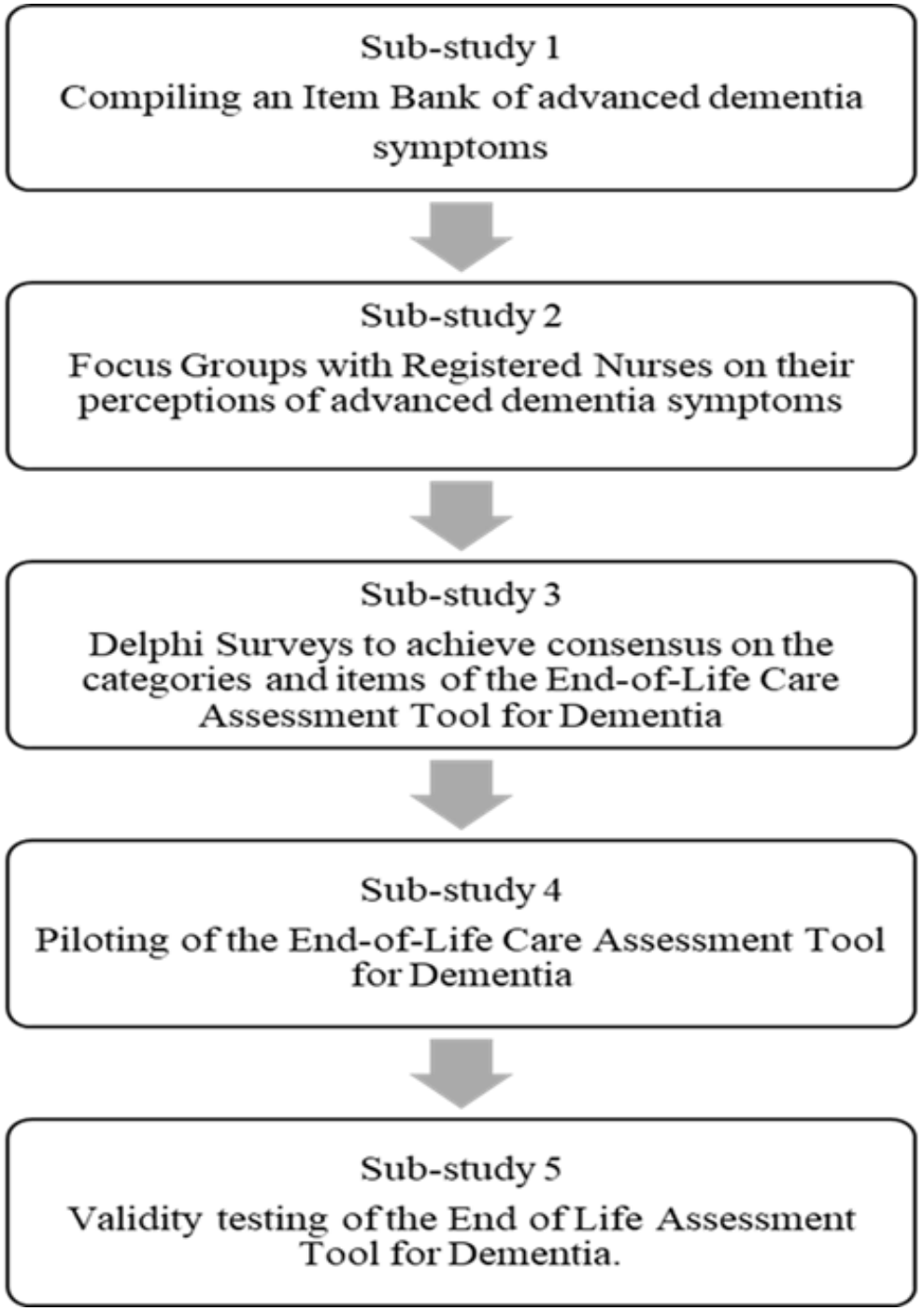
From Uncertainty to Clarity: Assessing End-of-Life Care in Advanced Dementia

Dr Carolyn Bourke (Moir) RN

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

- 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		
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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.
- Free, 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
- Plus a review of the person's other clinical assessments

A TALE OF NEGLECT

39.2% of aged care residents experience neglect, or emotional or physical abuse

68% of aged care residents are malnourished, or at risk of malnutrition

61% of residents in 150 aged-care facilities are regularly taking psychiatric medication

A question of human rights!

- The Royal commission into Age Care Quality and Safety (2021) identified the urgent need for RNs to receive additional education on palliative care of persons living with advanced dementia

Why This Matters

1. People with advanced dementia have complex health needs

2. There will likely be unmet needs which may present as changed behaviours

3. Skilled nursing knowledge is critical to quality person-centred end-of-life care

Dementia-Specific Assessment in Practice

Understanding the person

- Documenting the life story of a person with dementia

Assessing a person's quality of life

Focused assessments

- Pain verbal and nonverbal
- Distress – Distress Observational Tool
- Understand changed behaviours
    - Maybe physical changes in the brain or response to the environment, health or medication and behaviour may be their way to communicate.
- IPOS-Dem is a proxy measure
- FAST functional scale
- Depression scales
- 4AT for detecting delirium
- Anxiety rating scales
- Cognitive assessments

Common palliative care assessments

While not specific for dementia

- Care workers use the Stop and Watch Early Warning Tool
- The SPICT™ screening tool refers to dementia
- Australia-modified Karnofsky Performance Status (AKPS)
- Symptom Assessment Scale (SAS)
- Modified Borg dyspnoea Scale (mBORG)
- Mini-Nutritional Assessment Short-Form
- Rockwood frailty scale
- Braden PI risk
- Oral assessment

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

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)

Instructions for using the EoLC-ATD

- The End-of-Life Care Assessment Tool for Dementia (EoLC-ATD) consists of 27 items within six (6) constructs (global cognition, personhood, behaviour, function, physiological and psychological).

Preparation

- Review previous assessment data, care plans and other recorded information to determine symptoms according to the EoLC-ATD items.
- Review medications and laboratory test results for additional information on how these might impact or influence symptoms.

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EMPIRICAL RESEARCH MIXED METHODS OPEN ACCESS

Development and Validation of the End-of-Life Assessment Tool for Advanced Dementia: A Multi Method Study

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ABSTRACT

Aims: To develop and validate the End-of-Life Care Assessment Tool for Dementia (EoLC-ATD).

Design: A methodological study with multiple phases.

Methods: Five sub-studies comprising: a review of 90 validated dementia measures to compile an item bank of advanced dementia symptoms; focus groups with registered nurses on advanced dementia symptom identification and relevance of item bank inclusions; Delphi surveys with dementia experts seeking consensus on the EoLC-ATD constructs and items; pilot testing of the EoLC-ATD; and field testing of the EoLC-ATD in persons with dementia.

Results: The item-bank included 180 symptoms, most of which focus group nurses ($n = 17$) identified as occurring in advanced dementia. Delphi surveys with dementia experts ($n = 31$) achieved 70% consensus for 25 of 26 EoLC-ATD items. Pilot testing of the EoLC-ATD by two nurses in eight persons with dementia showed good agreement for six constructs (Cohen's Kappa 0.856–0.927) and 26 items (Cronbach's alpha 77.0). An 'other sympto' item was included following RN recommendation. The 27-item EoLC-ATD field tested by 17 nurses in persons with dementia ($n = 113$) accurately identified advanced dementia symptoms (Cronbach's alpha 77.0, $p < 0.001$). Mortality at 180 days after baseline EoLC-ATD was significant ($p < 0.001$, area under the ROC curve $p = 0.769$).

Conclusion: The EoLC-ATD accurately and reliably identified symptoms of advanced dementia.

Implications for the Profession and/or Patient Care: The EoLC-ATD provides registered nurses with a single measure of advanced dementia symptoms that will help in identifying symptom-responsive palliative care requirements.

Impact: The EoLC-ATD will address the current lack of a validated dementia symptom measure for use by aged care home registered nurses to identify unique palliative and end-of-life care needs according to presenting symptoms in persons living with advanced dementia.

Reporting Method: STROBE Statement for cohort and mixed methods studies.

Patient or Public Contribution: An eight-member Expert Advisory Group, which provided guidance and advice throughout the study, was composed of three carers of persons living with dementia, two dementia care clinicians, a dementia care clinical educator, and two dementia clinician researchers.

Applying the EoLC-ATD

Prepare

- Know the tool, process, and scoring before using it
- Gather information
- Talk with the person in a quiet, low-distraction space
- Ask staff and family/carers about symptoms and changes
- Observe mood, behaviour, engagement, withdrawal/anxiety

Assessment Timeframe

- Assess symptoms over the past 7 days

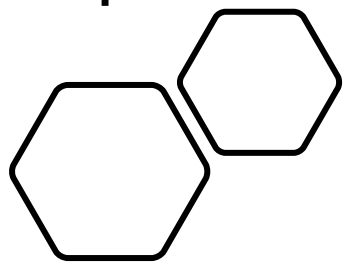
Scoring

- YES = present (last 7 days) → 1 point
- NO = not present → 0 points
- No half scores
- Record other symptoms (Item 27)
- Total score
- Out of 27
- >14 → advanced dementia

Actions

- Use additional tools as needed (e.g. PAINAD, 4AT)
- Communicate and care planning
- Repeat every 3–6 months and track changes

Next Steps



认知障碍症安宁疗护评估工具 (EoLC-ATD)

请回顾过去七天内，患者是否存在以下症状，并回答 是 / 否。

Thank you
Stay connected

- **Email:** Carolyn.bourke@uts.edu.au
- **Visit ELDAC:** www.eldac.com.au
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