

**A COMPARISON OF PALLIATIVE CARE OUTCOME MEASURES USED  
TO ASSESS THE QUALITY OF PALLIATIVE CARE PROVIDED IN  
RESIDENTIAL AGED CARE FACILITIES: A SYSTEMATIC REVIEW**

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## **BACKGROUND**

It is now recognised that palliative care in residential aged care facilities (RACFs) is important, particularly for people with non-cancer disease. While Australia leads the world with the first evidence-based guidelines for a palliative approach in this setting<sup>[1]</sup> limited research has been undertaken in measuring the extent to which these guidelines and other practice initiatives will impact on resident and family outcomes. This is due in part to the difficulties of measuring outcomes in palliative care in these settings and particularly the lack of evidence for the validity of measurement tools in palliative care. Despite these problems measuring outcomes is important for the development of high quality care, particularly in new settings where new models of care are being developed.

### **Domains of palliative care**

While there is debate on which are the most appropriate outcome measures for palliative care, there is widespread consensus among professionals as to what are the core domains of palliative care. In the United States, the National Consensus Project for Quality Palliative Care (NCP) and the National Quality Forum's (NQF's) Framework and Preferred Practices for a Palliative and Hospice Care Quality Project<sup>[2]</sup> identify eight domains: (1) structure and process of care, (2) physical aspects of care, (3) psychosocial and psychiatric aspects of care, (4) social aspects of care, (5) spiritual, religious, and existential aspects of care, (6) cultural aspects of care, (7) care of the imminently dying patient, and (8) ethical and legal aspects of care.

Similarly, Mularski et al<sup>[3]</sup> proposed nine outcome domains for evaluation of palliative care and end-of-life clinical trials. These domains are: (1) symptom management, (2) whole person and maintaining quality of life, (3) functional aspects, (4) satisfaction, (5) relationships, (6) decision-making and care planning, (7) continuity and communication, (8) family burden and wellbeing, and (9) quality of death and end-of-life experience.

While both these domain sets are from the health professional's perspective, Howell and Brazil<sup>[4]</sup> conducted a meta-synthesis of patient and family perspectives of what constitutes quality end of life care. They suggest the following domains: (1) pain and symptom management, (2) dying process not prolonged, (3) preparation for death, (4) support of family and friends, (5) supported decision-making, (6) spiritual support and meaning, (7) holistic and individualised care, and (8) death in a supportive environment in location of choice. Other researchers offer similar domains that should be included in measuring palliative care<sup>[5]</sup>.

This review will consider palliative outcome measures that assess the quality of palliative care provided to the resident and are multidimensional, that is, address at least two of the domains identified by Mularski et al<sup>[3]</sup>.

### **Existing reviews of palliative care outcome measures**

No Cochrane or Joanna Briggs Institute reviews of the psychometric properties of palliative care outcome measures specific to residential aged care facilities are available. Although systematic reviews have been conducted to identify outcome measures for use in assessing quality of palliative care these are usually centred around individuals with cancer or those receiving care in their own home, a palliative

care inpatient unit or a hospital. Therefore the results are not transferrable to the residential aged care setting<sup>[3, 5-8]</sup>. Other reviews have focused on satisfaction with care at the end of life<sup>[9, 10]</sup> or on current practice in providing end of life care in residential aged care facilities<sup>[11]</sup>.

The review by Hearn and Higginson<sup>[6]</sup> of outcome measures in palliative care specifically for patients with advanced cancer identified twelve measures but none had been used in residential aged care facilities.

A systematic review conducted in the development of *The Toolkit at the End of Life* (<http://www.chcr.brown.edu/pcoc/toolkit.htm>) found 20 outcome measures suitable to measure quality of palliative care and satisfaction. While this systematic review provides an extensive summary of measures available for palliative care a number of limitations exist which are pertinent for the proposed review. Firstly the literature is current only to the year 2000, search terms were limited and measures that were included were those which were accessible and easy to use<sup>[12]</sup>. Furthermore the review was not specifically focused on measures suitable for use in residential aged care facilities. As such only one measure recommended in the toolkit has been used in residential care – this measure is the *Afterdeath Bereaved Family Member Survey (Nursing Home version)*. This survey is designed to measure the family member's perspective regarding the extent to which a health care institution met the needs and expectations of a dying person and his/her family members. A more recent review conducted by the Agency for Healthcare Research and Quality with searches up to September 2004 identified a further six measures not included in the Toolkit. However, only two of these have been used in residential aged care facilities – the Quality of Dying and Death instrument and the Palliative Outcome Scale.

While both these reviews identified three measures that may be appropriate for use in RACFs neither of these systematic reviews examined the psychometric properties of these measures using published criteria<sup>[13]</sup>. Nor did they include an assessment of feasibility for use in residential aged care facilities, which would have enabled comparison between measures. The proposed systematic review aims to address these issues by determining - using published criteria - the reliability, validity and feasibility of these and other palliative care outcome measures that assess the quality of palliative care provided to people living in residential aged care facilities.

## **REVIEW QUESTION/OBJECTIVES**

The overall objective is to measure the psychometric properties (reliability/validity) and feasibility of palliative outcome measures used to assess the quality of palliative care provided in residential aged care facilities.

The more specific objectives are to:

1. Determine the reliability (inter-rater or test-retest) of these outcome measures used to assess the quality of palliative care provided in residential aged care facilities.
2. Determine the validity (content, criterion, construct, internal consistency) of these outcome measures used to assess the quality of palliative care provided in residential aged care facilities.
3. Determine the feasibility of the outcome measures used to assess the quality of palliative care provided in residential aged care facilities.

## **CRITERIA FOR CONSIDERING STUDIES FOR THIS REVIEW**

### **Types of studies**

This review will consider the following study types:

- randomised control trials
- quasi-experimental studies
- cohort studies
- case control studies
- observational studies without control group

### **Types of participants**

The review will consider studies that assess the quality of palliative care that has been provided to people living in residential aged care facilities and their family members.

### **Types of interventions**

This review will consider studies reporting on the psychometric properties of palliative care outcome measures that have been used in assessing the quality of palliative care provided in residential aged care facilities, including support to family. Measures may be those completed by a health professional, the person receiving care or their family. The outcome measure must cover at least two of the following domains<sup>[3]</sup>:

1. symptom management
2. whole person and maintaining quality of life
3. functional aspects
4. satisfaction
5. relationships
6. decision-making and care planning
7. continuity and communication
8. family burden and wellbeing
9. quality of death and end-of-life experience.

### **Types of outcomes**

This review will consider studies of outcome measures meeting the above criteria and where the following are reported: reliability, validity and feasibility of the measure.

## **SEARCH STRATEGY**

The search strategy aims to identify both English language published and unpublished studies. A three-step strategy will be followed, in which the initial phase will consist of searches of the CINAHL, MEDLINE and PsycINFO databases using keywords or terms. Second, a more extensive search will be performed using the appropriate Subject Headings and/or keywords/phrase/strategy for each of the databases listed below. Finally, the reference lists or bibliographies of identified reports and articles will be hand searched for additional relevant studies.

### **Databases**

Searches will be conducted for citations from the year 2000 to the present day. This date is considered appropriate as the Toolkit systematic review considered studies up to 2000. While this duplicates searching done by the Agency for Healthcare Research and Quality (AHRQ) systematic review which included searches up to September

2004, the specific search strategy for this review only included the MeSH heading 'Residential Facilities'. In the proposed review the search strategy for residential aged care facilities will be expanded. This will serve as a checking mechanism to ensure all relevant studies included in the AHRQ systematic review up to 2004 are captured in the proposed search strategies.

The databases to be searched will include:

PsycINFO  
MEDLINE  
CINAHL  
PsycARTICLES  
Ageline  
EMBASE  
APAIS Health  
Current Contents  
Digital Dissertations  
Social Science Citation Index  
Sociological Abstracts  
NHMRC guidelines  
Pre-CINAHL  
Professional Development Collection  
Cochrane Central Register of Controlled Trials (CENTRAL)  
AustHealth  
EBM Reviews

### **Hand searching**

Hand searching will be conducted through the following specialised relevant journals on palliative and aged care that are not indexed in the electronic databases.

1. American Journal of Hospice and Palliative Care
2. Annals of Long Term Care:
3. Clinical Care and Aging
4. Journal of Hospice and Palliative Nursing
5. Journal of Palliative Care
6. Journal of Palliative Medicine
7. International Journal of Palliative Nursing
8. Nursing Homes Long Term Care Management
9. Palliative Medicine
10. Palliative and Supportive Care
11. Progress in Palliative Care

### **Grey literature**

The grey literature search will consist of:

- searching reference lists or bibliographies of included articles
- contacting authors who may be knowledgeable about the phenomena of interest for further published, un-published or ongoing studies
- conducting an online search of databases and websites including:
  - CareSearch (online resource of palliative care and information)  
<http://www.caresearch.com.au/home/Home/tabid/98/Default.aspx>
  - Google Scholar

- PsycEXTRA
- National Institute of Clinical Studies
- Australian Centre for Evidence Based Clinical Practice (<http://www.acebcp.org.au>)
- Alzheimer's Disease Education and Referral Centre Clinical Trials Database *host*: Food and Drug Administration and the National Institute on Aging (<http://www.alzheimers.org/trials/index.html>)
- National Institutes of Health (NIH) Clinical Trials Database *host*: NIH (<http://clinicaltrials.gov/ct>)
- National Institute of Clinical Studies (<http://www.med.monash.edu.au/healthservices/cce/index.html>)
- Clinical Medicine Netprints Collection, <http://clinmed.netprints.org/collections/>
- Palliative and Supportive Care Specialist Library [National Health Service], <http://www.library.nhs.uk/palliative/>

### **Initial keywords or terms**

Residential facilities OR residential aged care OR long term care OR nursing home OR care homes OR aged care facilities OR old age homes OR homes for the aged  
 Clinical audit OR medical audit OR nursing audit  
 Palliative care OR hospice care OR terminal care OR end of life care  
 Quality of care, quality of death, quality assurance, outcome measure, intervention, instrument, assessment tools, validity, reliability and feasibility.

## **METHODS OF THE REVIEW**

### **Data retrieval**

All studies identified by the database searches will be critically appraised for relevance to the review based on the title and abstract. For studies that appear to meet the inclusion criteria, the full paper will be retrieved and will be assessed for relevance to the review criteria.

### **Assessment of methodological quality**

Studies will be assessed by two independent reviewers for methodological quality prior to inclusion in the review using an appraisal checklist developed for the review based on the review methods of Zwakhalen et al <sup>[13]</sup> to evaluate reliability, validity and feasibility (Appendices 1 and 2). Any disagreements that arise between the reviewers will be resolved by a third reviewer.

### **Data extraction**

Data will be extracted using a data extraction tool developed for the review and based on the ten psychometric properties identified by Zwakhalen et al <sup>[13]</sup> (Appendix 3).

### **Data synthesis**

Evidence in relation to the psychometric properties of outcome measures will be categorised according to the ten psychometric properties being tested and collected according to the data extraction tool. Narrative summaries of the evidence and tables summarising the evidence will be provided.

### **Potential conflict(s) of interest**

None known.

## REFERENCES

1. Commonwealth of Australia, *Guidelines for a palliative approach in residential aged care facilities - NHMRC endorsed edition*. 2006: Canberra.
2. National Consensus Project for Quality Palliative Care. *Clinical practice guidelines for quality palliative care*. 2004. Available from:<http://www.nationalconsensusproject.org>.
3. Mularski, R., Rosenfeld, K., Coons, S., Dueck, A., Cella, D., Feuer, D., Lipscomb, J., Karpeh, M., Mosich, J., Sloan, J., Krouse, R. Measuring outcomes in randomized prospective trials in palliative care. *Journal of Pain and Symptom Management*. 2007; 34 (1 Suppl): S7-S19.
4. Howell, D., Brazil, K. Reaching common ground: a patient-family-based conceptual framework of quality EOL care. *Journal of Palliative Care*. 2005; 21(1): 19-26.
5. The Toolkit at the End of Life. 2008. Available from:<http://www.chcr.brown.edu/pcoc/toolkit.htm>.
6. Hearn, J., Higginson, I.J. *Outcome measures in palliative care for advanced cancer patients: a review*. *J Public Health*, 1997; 19(2): 193-199.
7. Mayland, C., Williams, E., Ellershaw, J. How well do current instruments using bereaved relatives' views evaluate care for dying patients? *Palliative Medicine*. 2008; 22: 133-144.
8. Mularski, R., Dy, S., Shugarman, L., Lynn, J., Shekelle, P., Morton, S., Sun, V., Hughes, R., Hilton, L., Maglione, M., Rhodes, S., Rolon, C., Lorenz, K. A systematic review of measures of End-of-Life Care and Its Outcomes. *Health Services Research* 2007; 42(5): 1848-1870.
9. Aspinal, F., Addington-Hall, J., Hughes, R., Higginson, I.J. Using satisfaction to measure the quality of palliative care: a review of the literature. *Journal of Advanced Nursing*, 2003; 42(4): 324-339.
10. Moss, S., Shugarman, L., Lorenz, K., Mularski, R., Lynn, J. A systematic review of satisfaction with care at the End of Life. *Journal of the American Geriatrics Society*, 2008; 56: 124-129.
11. Parker Oliver, D., Porock, D., Zweig, S. End-of-Life Care in U.S. Nursing Homes: A review of the evidence. *Journal of the American Medical Directors Association*, 2004; 5: 147-155.
12. Lorenz, K., Morton, S., Mularski, R., Shugarman, L., Sun, V., Wilkinson, A., Maglione, M., Shekelle, P. *End-of-Life Care and Outcomes. Summary, Evidence Report/Technology Assessment No 110 (Prepared by the Southern California Evidence-based Practice Centre, under Contract No. 290-02-003, A.P.N. 05-E004-1, Editor*. 2004: Rockville.
13. Zwakhalen, S., Hamers, J., Abu-Saad, H., Berger, M. Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools. *BMC Geriatrics*. 2006; 6(3): doi:10.1186/1471-2318-6-3.

## Appendix 1 - Criteria for psychometric review

Aspect	Score	Description
<b>Origin of items</b>	2	Items specifically collected for use in elderly people in RACFs
	1	Items were modified for use in elderly people in RACFs
	0	Items originated from a scale developed from another population
<b>Number of participants</b>	2	If $N \geq 100$ and the number of elderly people in RACFs was considerable relative to the number of items or $50 < N < 100$ and corrected for multiple testing
	1	If $50 < N < 100$ and the number of elderly people in RACFs included was considerable relative to the number of items or $N < 50$ and corrected for multiple testing
	0	If $N < 50$ , not corrected for multiple testing and small number of elderly people in RACFs included
<b>Content validity</b>	2	If scale seems to cover all important items/dimensions (in the reviewers' opinion), items were collected for the specific population and different sources/methods were used to collect items
	1	If the scale seems to cover important items/dimensions to a moderate extent (in the reviewers' opinion)
	0	If the scale does not seem to cover the important items/dimensions (in the reviewers' opinion)
<b>Criterion validity</b>	2	If correlates acceptable to high ( $r > 0.60$ ) according to the gold standard or according to silver standard and sensitivity/specificity is determined to be acceptable
	1	If correlates moderate - acceptable ( $0.40 < r < 0.60$ ) according to the gold standard or according to silver standard
	0	If correlates low ( $r < 0.40$ ) or no information is provided
<b>Construct validity in relation to other tool</b>	2	If correlates with other palliative outcome measure acceptable to high ( $r > 0.60$ )
	1	If correlates with other palliative outcome measures are moderate - ( $0.40 < r < 0.60$ )
	0	If correlates are low ( $r < 0.40$ ) or no information is provided
<b>Construct validity – differentiation</b>	2	If scale differentiates well (in the reviewers' opinion) between palliative care provided or not provided
	1	If scale differentiates moderately well (in the reviewers' opinion) between palliative care provided or not provided
	0	If the scale does not differentiate or no information is provided
<b>Homogeneity</b>	2	If $0.70 < \alpha < 0.90$
	1	If $\alpha > 0.90$ or $> 0.60$ $\alpha < 0.70$
	0	If $\alpha$ is $< 0.60$ or no information is provided
<b>Inter-rater reliability</b>	2	If reliability coefficient $> 0.80$
	1	If $0.60 < \text{reliability coefficient} < 0.80$
	0	If reliability coefficient $< 0.60$ or no information is provided
<b>Intra-rater and/or test-retest reliability</b>	2	If reliability coefficient $> 0.80$
	1	If $0.60 < \text{reliability coefficient} < 0.80$
	0	If reliability coefficient $< 0.60$ or no information is provided
<b>Feasibility</b>	2	If scale is short, manageable with instructions, scoring interpretations
	1	If scale is manageable (one format)
	0	If scale is more complex

## Appendix 2 – Critical appraisal form for psychometric review

Author: \_\_\_\_\_ Record No: \_\_\_\_\_

Journal: \_\_\_\_\_ Year: \_\_\_\_\_

Reviewer: \_\_\_\_\_

	Criteria	Score		
		0	1	2
1	Origin of items			
2	Number of participants			
3	Content validity			
4	Criterion validity			
5	Construct validity in relation to other measure			
6	Construct validity - differentiation			
7	Homogeneity			
8	Inter-rater reliability			
9	Intra-rater reliability and/or test-retest reliability			
10	Feasibility			
	Totals			

Overall score (range 0 – 20) /20

Include  Exclude  Seek further information

Comments (including reason for exclusion)

**Appendix 3 - Extraction form for psychometric review**

**Author:** \_\_\_\_\_ **Record No:** \_\_\_\_\_

**Journal:** \_\_\_\_\_ **Year:** \_\_\_\_\_

**Reviewer:** \_\_\_\_\_

**Study Method**    RCT     Quasi RCT     Longitudinal   
                          Retrospective     Observational

Participants	
Setting	
Number of items/dimensions	
Scoring range	
Origin of items	
Content validity	
Criterion validity	
Construct validity in relation to other measure	
Construct validity - differentiation	
Homogeneity	
Inter-rater reliability	
Intra-rater reliability and/or test-retest reliability	
Feasibility	

Authors Conclusions

Reviewers Conclusions