

# A systematic review of outcome measures suitable for use in residential aged care

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# Palliative care in residential aged care

- Recognition of the role RACF have in providing palliative care
- Evidence-based guidelines for a palliative approach
- Limited research on impact of care on palliative outcomes in this setting
- No consensus on what outcomes should be measured.
- Measures designed for cancer care or specialist services may not be appropriate

# Aim of the systematic review

- 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
- Conducted as a Joanna Briggs Institute Systematic Review

# Inclusion criteria

- Articles published between 2000 and 2008
- Outcome measures that have been used in assessing the quality of palliative care provided in residential aged care facilities.
- Must report on the psychometric properties - validity, reliability or feasibility
- Measure may be those completed by a health professional, the person receiving care or their family.
- Measure may be prospective or retrospective
- Measure must cover more than one palliative care domain

# Core domains of palliative care

- Symptom management
- Whole person and maintaining quality of life
- Functional aspects
- Satisfaction
- Relationships
- Decision-making and care planning
- Continuity and communication
- Family burden and wellbeing
- Quality of death and end of life experience

(Mularski et al 2007)

# Databases searched- 1/1/2000 - 12/9/2008

- Medline
- Cinahl
- PsychInfo
- PsycArticles
- Ageline
- Embase
- APAIS Health
- Cochrane
- Digital Dissertations
- Social Science Citation Index
- Sociological Abstracts
- Aust Health
- EBM Reviews

Hand searching of key journals and grey literature

# Initial keywords

- Long term care or residential aged care or nursing home or care home or aged care facilities

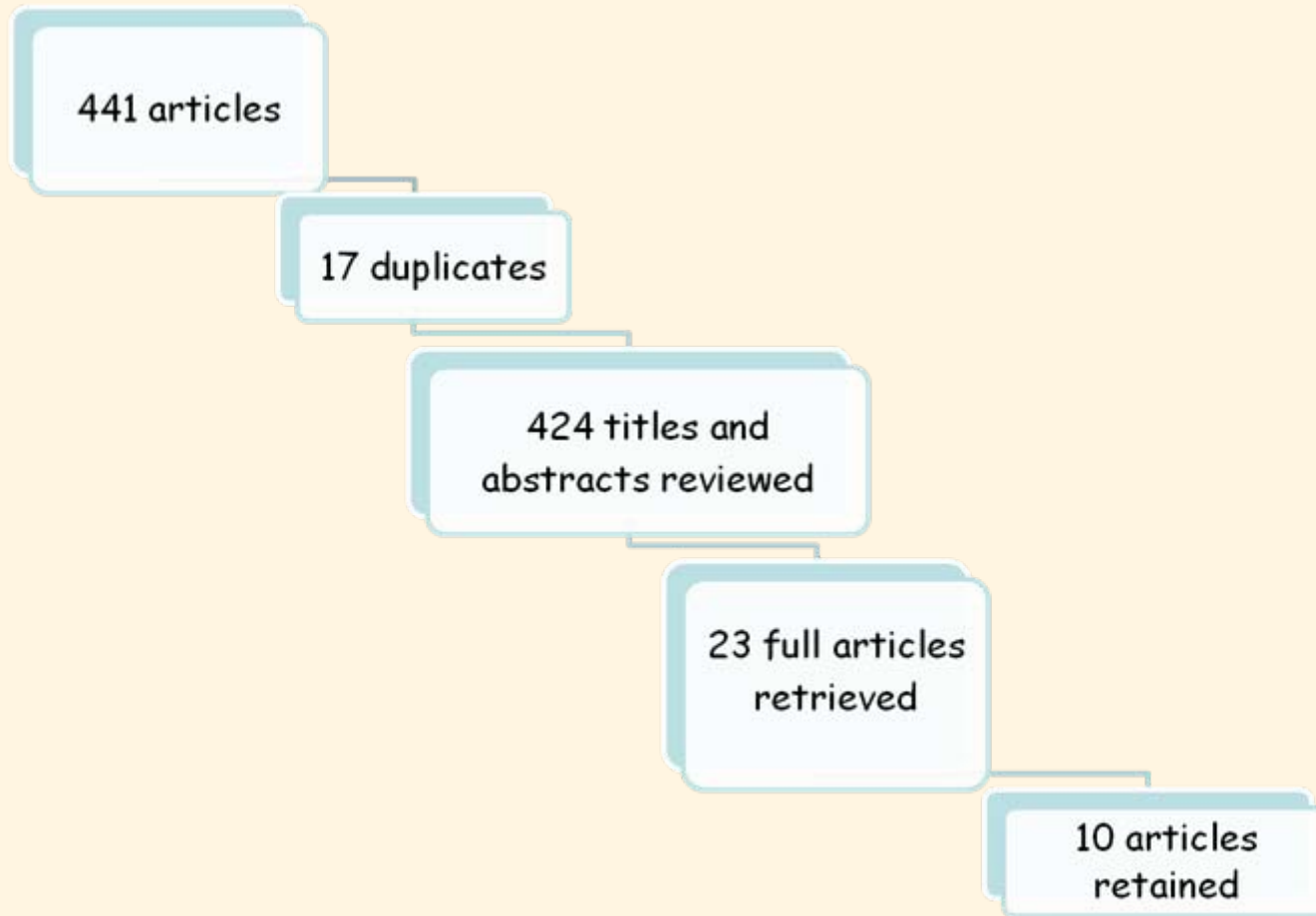
AND

- Palliative care or hospice care or terminal care or end of life care

AND

- Quality of care or quality of death or outcome measure or assessment tool or validity or reliability or feasibility

# Search results



# Ten Outcome Measures

- The Quality of Dying in Long-Term Care (QOD-LTC /QOD-LTC-C)
- Family Perceptions of Care Scale (FPCS)
- End of Life in Dementia Scales (EOLD) which consists of 3 scales - SM-EOLD, SW-EOLD and CAD-EOLD
- The Palliative Outcome Scale (POS)
- Family Assessment of Treatment at End of Life Survey (FATE)
- Toolkit After-Death Bereaved Family Member Interview (Toolkit Interview)
- Quality of Dying and Death (QODD)
- The Quality-of-Life Concerns in the End of Life Questionnaire (QOLC-E)
- The modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E)
- The Resident Assessment Instrument for Palliative Care (RAI-PC)

# Critical appraisal of quality

Based on checklist by Zwakhalen et al (2006)

10 questions (rated 0, 1 or 2)

1. Origin of items
2. Number of participants
3. Content validity
4. Criterion validity
5. Construct validity - related to another measure
6. Construct validity - differentiation
7. Internal consistency
8. Inter-rater reliability
9. Intra or test-retest reliability
10. Feasibility

## Articles reporting data specific to RACF

| Measure                 | QOD-LTC/QOD-LTC-C           | FPCS                                      | EOLD Scales  | POS                                     |
|-------------------------|-----------------------------|---|--|---|
| Origin                  | QUAL-E<br>Not RACF specific | Lit review<br>Interviews<br>RACF specific | Expert panel<br>Dementia specific<br>Not RACF specific | Cancer patients<br>Not RACF<br>specific |
| Participants            | 439 bereaved carers         | 203 bereaved carers                       | 156 bereaved carers                                    | 328 residents                           |
| Content validity        | Yes                         | Yes                                       | Yes  | Yes                                     |
| Criterion validity      | No                          | No  | No   | No                                      |
| Construct validity 1    | No                          | No  | Yes  | No                                      |
| Construct validity 2    | No                          | Yes                                       | No   | Yes                                     |
| Internal consistency    | Alpha -0.66                 | Alpha - 0.85                              | Alpha 0.74 - 0.9                                       | No                                      |
| Inter-rater reliability | ICC - 0.345                 | No  | No   | No                                      |
| Test retest reliability | No                          | No  | No   | No                                      |
| Feasibility             | Yes                         | Yes                                       | Yes  | Yes                                     |
| Quality rating          | 8                           | 9   | 12   | 6                                       |

# Articles reporting data not specific to RACF

| Measure                 | FATE                       | Toolkit Interview           | QODD                        | QOLC-E                      | mQOLC-E                 | RAI-PC                |
|-------------------------|----------------------------|-----------------------------|-----------------------------|-----------------------------|-------------------------|-----------------------|
| Origin                  | Interviews                 | Focus groups                | Focus groups                | Qual study                  | QOLC-E                  | RAI                   |
| Participants            | Bereaved carers<br>6% RACF | Bereaved carers<br>21% RACF | Bereaved carers<br>24% RACF | COPD/Cancer Pts<br>26% RACF | Outpatients<br>51% RACF | Residents<br>33% RACF |
| Content validity        | Yes                        | Yes                         | Yes                         | Yes                         | Yes                     | Yes                   |
| Criterion validity      | Yes                        | Yes                         | Yes                         | Yes                         | Yes                     | No                    |
| Construct validity 1    | No                         | No                          | Yes                         | Yes                         | Yes                     | No                    |
| Construct validity 2    | Yes                        | Yes                         | Yes                         | No                          | No                      | No                    |
| Internal consistency    | Alpha 0.9                  | Alpha 0.58-0.87             | Alpha 0.89                  | Alpha 0.87                  | Alpha 0.89              | No                    |
| Inter-rater reliability | No                         | No                          | No                          | No                          | ICC 0.83                | Kappa 0.75            |
| Test retest reliability | No                         | ICC 0.4                     | No                          | No                          | No                      | No                    |
| Feasibility             | Yes                        | Yes                         | Yes                         | Yes                         | Yes                     | Yes                   |
| Quality rating          | 9                          | 10                          | 10                          | 10                          | 11                      | 8                     |

# Family Perceptions of Care Scale

(Vohra et al 2004)

- Retrospective - bereaved carers
- Developed specifically for residential aged care
- Psychometric testing was specific to residential aged care
- Requires further testing for inter-rater reliability
- 25 items
- Four factors
  1. Resident care
  2. Family support
  3. Communication
  4. Rooming
- Suitable for postal but 7 item response less suitable for phone

# QOD-LTC/QOD LTC-C

( Munn et al 2007)

- Retrospective - bereaved carers
- Developed from QUAL-E (not residential specific)
- Psychometric testing was specific to residential aged care
- Requires further testing for criterion and construct validity
- Two versions - cognitively impaired/intact
- QOD-LTC - 11 items
  - Three factors
    1. Closure
    2. Preparatory tasks
    3. Personhood
  - QOD-LTC -C - 23 items
    - Five factors
      1. Closure
      2. Preparatory tasks
      3. Sense of purpose
      4. Control
      5. Social connection

# Toolkit Interview

(Teno et al 2001)

- Retrospective
  - Developed for use across settings
  - Has a nursing home version
  - Good as phone interview or postal- well developed script
  - Needs further psychometric testing in residential care
- 36 items - Eight domains
    1. Closure
    2. Informing and making decisions
    3. Advance care planning
    4. Achieving control and respect
    5. Family emotional support
    6. Coordination
    7. Self-efficacy
    8. Patient focused family centred care

# Summary

- Only the FPCS was developed and psychometrically tested specifically in RACFs
- Those adapted from other settings and populations should be checked to ensure questions are appropriate
- Quality - no measure scored above 12/20
- Prospective vs Retrospective ratings
- Disease specific - dementia