



The development and validation of instruments to measure dignity-protective continence care for care-dependent older people in residential aged care facilities: A study protocol

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Abstract

Aims: To develop and validate two instruments to measure dignity-protective continence care for care-dependent older people in residential aged care facilities: one instrument to be completed by care recipients and another for healthcare professionals.

Methods: The first phase of the project will involve a review of literature to identify the attributes of “dignity-protective continence care” for older people, which will be used to design the initial drafts of the instruments. Thereafter the Delphi survey technique will be used to establish the face and content validity of the draft instruments with three purposive samples; (a) care recipients (care-dependent older people with decisional capacity), (b) formal carers (nurses and personal care workers from residential aged care facilities, and (c) healthcare professionals with gerontological expertise in the management of incontinence. After instrument development, a large cross-sectional survey of care recipients and formal carers will be conducted to establish the internal

consistency and construct validity of the instruments. This will be followed by a series of tests to establish their test-retest reliability.

Conclusion: The completed research will result in two reliable and valid instruments that will support broader efforts to ensure that care practices in residential aged care facilities do not violate the dignity of care-dependent older people with continence care needs, and allow care partners and providers to act upon the results.

KEYWORDS

concept analysis, dignity, incontinence, instrument, measurement, older people, questionnaire

1 | INTRODUCTION

In recent years, there has been an increased focus on the need to better uphold and promote the dignity of people requiring long-term care in facilities, such as residential aged care facilities* (RACFs)^{1,2} and hospitals.^{3,4} In Australia, the recent royal commission into quality and safety in aged care¹ found that more than half of the complaints made related to compromises to personal dignity. Similarly, the 2018 care quality commission NHS survey of 76 668 inpatients in the UK found almost one fifth did not feel that they were treated with respect and dignity at all times.⁵

Arguably, incontinence and the care required for its management, threatens or undermines dignity, particularly in older people.⁶⁻⁸ Incontinence is a common and distressing symptom that disproportionately affects people who require care in a RACF. Australia has just over 2700 RACFs operated by 870 approved providers.⁹ Approved providers of Australian RACFs are from a range of sectors, including religious (23.4%), charitable (18.3%), community (13.3%), for-profit (41%), and government (4%).⁹

Approximately 223 000 Australians (5.6%) currently access permanent residential aged care.⁹ By 2050, the demand for aged care will increase to more than 3.5 million people per year.¹⁰ The average age on admission to RACF is 82.3 years for men and 84.6 years for women.⁹ In 2010, 128 473 (70.9%) of these care recipients were incontinent of urine, faeces or both.¹¹ By 2030, the number of people living with incontinence in RACF is projected to double and increase to 253 113 people.¹¹

People living in RACFs also have high rates of care-dependence and dementia and immobility,⁹ both of which increase the risk of incontinence. In the USA, 89.3% of the 1 347 600 people living in nursing homes rely on staff for help to reach and use the toilet.¹² Many of these care recipients are not cured of incontinence, and rely on another person to help them maintain continence or manage the symptom as a chronic condition, and/or they may use incontinence products.¹³

The etiology of incontinence in RACFs is multifactorial and is highly associated with impairments in cognition and physical function.¹⁴ A recent model of risk factors associated with urinary incontinence (UI) among institutional older adults with dementia revealed UI in this population was significantly related to impaired ability to perform activity of daily living.¹⁵ Indeed, in a population-based study of 54 816 people aged 60 to 89 with dementia and an age-gender stratified sample of 205,795 people without dementia, Grant et al,¹⁶ found the adjusted rate ratio for first diagnosis of UI was 3.2 (2.7-3.7) in men and 2.7 (2.3-3.2) in women, and for fecal incontinence was 6.0 (5.1-7.0) in men and 4.5 (3.8-5.2) in women.

Organizational factors, such as the number of registered nurses (RNs) to care recipients also influence the risk of UI in RACFs as does the location of the facility, that is, a higher number of RNs to patients, and urban location is associated with better continence outcomes for care recipients.¹⁷ In 2016, 70% of the 235 764 staff who provided direct care in Australian RACFs were personal care workers, followed by RNs (15%), enrolled nurses (10%), and allied health professionals/assistants (5%).¹⁸ A recent report of national and international staffing requirements to inform RACF services in Australia found 57% of care recipients in Australian RACFs are in homes with staffing that are comparable to the one or two stars in five-star rating system used in the USA.¹⁹

Because providing continence care necessarily involves transgressing their personal space and infringing social norms about privacy and touch, we speculate that

*The Australian Institute for Health and Welfare defines a RACF as: A special-purpose facility which provides accommodation and other types of support, including assistance with day-to-day living, intensive forms of care, and assistance towards independent living, to frail and aged residents. Facilities are accredited by the Aged Care Standards and Accreditation Agency Ltd to receive funding from the Australian Government through residential aged care subsidies <https://meteor.aihw.gov.au/content/index.phtml/itemId/384424>.

individuals who are care-dependent are at risk of violations to their personal dignity, particularly if they are also cognitively impaired and lack decisional capacity.²⁰ Despite this possible risk, existing instruments designed to evaluate the impact of incontinence, such as the incontinence impact questionnaire (IIQ, or IIQ-7),²¹ the king's health questionnaire,²² the incontinence quality of life questionnaire,²³ and the ICIQ-Cog²⁴ ignore this dimension of care.

We suggest "dignity" could function as a value or guiding principle in an ethic and measurement of care for care-dependent people who require continence care.^{20,25} Protecting patients' dignity is a fundamental aspect of care,^{26,27} however as there is no method to quantify violations to the dignity of this vulnerable group of people, major challenges exist to implementing and evaluating dignity-protective continence care for individuals who are care-dependent.

2 | AIMS OF STUDY

To develop and validate two instruments to measure dignity-protective continence care for care-dependent older people in RACFs: one instrument for care recipients with decisional capacity to complete and another for healthcare professionals.

3 | MATERIALS AND METHODS

The study uses a mixed method approach with the following six interrelated stages:

- (1) A review of literature to identify the attributes of dignity-protective continence care for older people.
- (2) Use of information from stage 1 to draft the two instruments: one instrument for completion by care recipients to be titled *the dignity in continence care scale (self-report version)* and one for completion by healthcare professionals to be titled *the dignity in continence care scale (staff version)*.
- (3) A consultation with a purposive sample of RACF stakeholders to establish the face validity of the draft instruments for use in RACFs.
- (4) A Delphi survey of RACF stakeholders to establish the content validity of the draft instruments for use in RACFs.
- (5) A cross-sectional survey of RACF stakeholders to establish the internal consistency and construct validity of the draft instruments for use in RACFs.
- (6) A series of tests to determine if the draft instruments are reliable.

Stage 1: The initial design of instruments will be based on a literature review, termed a concept analysis. Concept analysis is a well-established methodology that has been used to analyze many key concepts in health and social care. Rodgers²⁸ highlights that it is the attributes that serve as the true definition of the concept under study and that the definition of the key attributes or the concept is the "primary accomplishment of a concept analysis."²⁸ To define these key concepts, the first four steps of Rodgers evolutionary method of concept analysis will be used.

- (1) Identify and name the concept of interest and its surrogate terms
- (2) Identify and select an appropriate sample for the data collection
- (3) Collect data relevant to identifying attributes and contextual bases of the concept
- (4) Analyze the data to identify key characteristics of the concept.²⁸

An iterative process will be adopted, beginning with a review of key guidelines about continence care from the International Continence Society's Continence Care Steering Group,²⁹ the UK National Health Service,³⁰ the Royal College of Physicians,³¹ the Association for Continence Advice,³² minimum standards for continence care in the UK,³³ the Continence Nurses Society of Australia,³⁴ the Wound, Ostomy and Continence Nurses Society³⁵ and guidelines from the International Consultation on Incontinence.³⁶ Information about dignity related to continence care will be extracted and used to support the development of the search strategy.

A specialist healthcare librarian will assist in developing a search strategy for each database (MEDLINE Ovid, Embase Ovid, PsycINFO, CINAHL EBSCO, Web of Science, Google Scholar, and Cochrane Complete, based on the one to be developed for MEDLINE (Ovid). MeSH terms will be added to complement the search. Key search terms will include truncation of key words, use of thesaurus terms and subject headings, and combining terms and search strings with the appropriate Boolean operators. Date and language (ie, English only) limiters will be applied to each database, with publications from 2009-2019.

All included records will be managed in covidence (cochrane's systematic review management software) to assist with the review process. Each reviewer will assess a different sample of 25 articles to ensure reliability in application of the inclusion and exclusion criteria. All records will be screened by a minimum of two reviewers and any discrepancies will be resolved via discussion. As screening will be conducted, conflicts will be automatically

identified by the covidence software, and these will be discussed by the review team until consensus is reached. The review process will be guided by the preferred reporting items for systematic reviews and meta-analyses, PRISMA-ScR check list³⁷ and a PRISMA flow chart will be used to illustrate all stages of the study selection.

Stage 2: The researchers will construct a draft of two instruments with reference to the attributes identified in stage 1 and with careful consideration to the content areas to be tested, the number of questions in each content area, the level of specificity desired and guidance about developing questions and questionnaire design.³⁸ We will aim to design an instrument that is simple, with familiar words, the response options will be exhaustive and mutually exclusive, questions on the same topic will be grouped together and proceed from general to specific, and response options will be carefully considered to optimize completion, that is, dichotomous response options will be avoided.^{39,40} Existing surveys designed for the same cohort, and which test similar concepts will be reviewed to identify a layout that is easy to understand and complete. All members of the research team will review these surveys and drafts.

Stage 3: The purpose of stage 3 is to establish the face validity of the draft instruments i.e. to determine if they “look like” a measure of the construct of interest from the perspective of the end user.⁴¹ A purposive sample of RACF care recipients who have decisional capacity (ie, have the capacity to opt into and consent to participate in research), RACF staff, and experts will review the instruments. The experts will consist of healthcare professionals and researchers with gerontological expertise in the management of incontinence. All participants will complete a survey indicating: (a) whether the items cover the range of issues that are important, (b) if the design of each instrument is appropriate for potential users, (c) if the terms and language are appropriate and understandable, and (d) their opinions about the feasibility of completing the instruments. They will also be given the opportunity to provide free-text comments.

Stage 4: The purpose of stage 4 is to establish the content validity of the instruments, that is, “the systematic examination of the test content to determine whether it covers a representative sample of the behavior domain to be measured.”⁴² Up to 40 experts (healthcare professionals and researchers who identify as having expertise in managing incontinence in RACFs) will be recruited. The Delphi survey technique based on guidelines from Hansson et al,⁴³ will guide the process of data collection, the number of rounds of feedback and the analysis. A Delphi survey is “a group facilitation technique, which is an iterative multistage process, designed to transform opinion into group consensus.”⁴³ Two to three

rounds of feedback are usually undertaken to reach consensus.⁴³

Participants will complete an anonymous online survey to rate the relevance and clarity of the draft instruments on a four-point rating scale, where one stands for an irrelevant item and four for an extremely relevant item. In addition to rating items for relevance, experts will be asked to give reason/comments if they score an item as low, that is, 1 or 2. Consistent with recommendations from Humphrey-Murto et al,⁴⁴ if 20% or more experts score an item as 1 or 2, the comments about the question will be used to refine the question and the revised questions will be circulated to participants who have agreed to further contact.

Stage 5: In stage 5, a large cross-sectional study will be conducted to establish the internal consistency and construct validity of the draft instruments. Two cohorts will be recruited to complete an online anonymous survey: (a) RACF care recipients with decisional capacity and (b) RACF staff (nurses and personal care workers). Based on previous studies on measuring dignity,⁴⁵ the recruitment target will be set at 50 to 100 care recipients and 50 to 200 staff. Care recipients will complete:

- A demographic form
- *The dignity in continence care scales (self-report version)*
- The inpatient dignity scale⁴⁵

The inpatient dignity scale⁴⁵ measures inpatients' expectations of—and satisfaction with—dignity in daily care. The English version of the scale consists of 21 items, of which 16 rate expectations and 18 rate satisfaction. The items address four topic areas:

- Respect as a human being
- Respect for personal feelings and time
- Respect for privacy
- Respect for autonomy.

Use of the inpatient dignity scale will enable examination of the relationship between dignity in overall care and the findings from the *dignity in continence care scale (self-report version)*.

The survey for RACF staff will consist of:

- A demographic form,
- *The dignity in continence care scale (staff version)*
- The team member perceptions of person-centered care (TM-PCC).⁴⁶

The TM-PCC is a brief psychometrically valid instrument for use in long-term care homes.⁴⁶ It can be used to assess PCC from the staff's perspectives. The instrument

consists of three components and 11 items: (a) Supporting social relationships (four items); (b) Familiarity with residents' preferences (four items), and (c) Meaningful resident-staff relationships (three items). A psychometric evaluation of the instrument revealed high reliability. Cronbach's α coefficient for all 11 items was 0.82. Internal consistency for the three components was generally high and ranged from 0.62 to 0.83. Average scores in each construct were high and ranged from 3.56 to 4.17 out of five. Using the TM-PCC in the current study will enable examination of any associations between staff perceptions of the person-centeredness of the care and staff perceptions of the extent to which continence care practices protect residents' dignity.

Stage 6: In the last stage of the study, the repeatability or test-retest reliability of the instruments will be established to determine how closely successive repeat measurements under the same conditions agree with one another.⁴⁷ A purposive subsample of 50 RACF residents and 50 RACF staff will complete the relevant instruments at one-time point and again 2 weeks later. The sample size is based on recommendations from Terwee et al⁴⁸ The timeframe has been selected on the finding that the test-retest reliability tends to reduce when the test reapplication is extended.⁴⁹ Specifically, "the time span between measurements will influence the interpretation of reliability in the test-retest; therefore, the time span from 10 to 14 days is considered adequate for the test and retest."⁴⁵

3.1 | Recruitment

A combination of recruitment approaches will be used, consistent with the different stakeholder groups and procedures for each stage. Participants who self-select to participate in stage 3 (face validity) will be recruited from a purposively selected public sector RACF in the Western regional area of Victoria, Australia. The nurse unit manager (NUM) (or delegate) of the participating unit will identify potential care recipients based on his/her professional knowledge of their decisional capacity and with reference to their medical records. She/he will provide them with verbal and written information about the research, including a patient information and consent form with the research team's contact details. If the care recipient expresses an interest to participate, the NUM (or delegate) will notify the research team who will then arrange a time to meet the care recipient to further explain the procedures and verify informed consent.

Experts who self-select to participate in stage 4 will be recruited through peak agencies that provide information and advocacy about incontinence and aged care. These

agencies will include information about the study in their promotional newsletters with a link to an online anonymous survey.

RACF residents and RACF staff who volunteer to complete the online anonymous cross-sectional survey (stage 5) will be recruited from a purposive sample of several large public sector RACFs in the western regional area of Victoria, Australia. Information about the research will be disseminated to the managers of these RACFs, providing a link to the online surveys and a flyer about the research for eligible residents and staff. The survey will include an option for participants to volunteer for stage 6.

3.2 | Ethics

The study will be carried out according to the National Statement on Ethical Conduct in Human Research⁵⁰ produced by the National Health and Medical Research Council of Australia. The ethics aspects of the study have been approved by the Human Research Ethics Committee of Deakin University and Barwon Health. Participation will be voluntary and individuals will self-select to participate. Completion and return of the online anonymous surveys in stages 4 and 5 will imply consent to participate. Written consent will be sought from care recipients and staff who volunteer to participate in stages 3 and 6.

4 | DATA ANALYSIS PLAN

Face validity statistical data from stage 3 will be reviewed and analyzed using descriptive statistics. Two members of the research team will independently review all free-text responses and assign codes to them using a deductive coding framework that is consistent with the survey questions. Differences in coding will be discussed within the team until consensus is reached. The researchers will base their final decision on the alignment of the feedback with current evidence.

To analyze data to determine the content validity of the instruments (stage 4), the content validity indices and the weighted κ will be calculated. Two content validity indices, the item-rated and scale-level content validity indices (I-CVI and S-CVI, respectively) will be estimated. The I-CVI, which measures the level of agreement between experts, will be determined for each item in the proposed questionnaire as the number of experts scoring the item as relevant (scored 3 or 4) divided by the total number of experts. The κ statistic on the other hand will be estimated to measure the degree of agreement beyond

chance agreement. Items will be deemed relevant and kept in the questionnaire only if $I\text{-CVI} \geq 0.78$ and $\kappa \geq 0.75$. In addition to item level statistics, the S-CVI will be estimated to measure average I-CVIs in the questionnaire, which is the sum of all I-CVIs divided by the total number of items in the questionnaire and is defined as good if $S\text{-CVI} > 0.90$.⁵¹

Data from the cross-sectional study (stage 5) will be summarized using frequencies with their percentages, means with standard deviations, and medians (with the 25th and 75th percentiles) will be used to summarize skewed interval data. Response rates and levels of missing data for each item will be determined. The internal consistency of the instrument will be assessed for question-question consistency using Cronbach's α coefficient. Values close to 0.7 will be considered satisfactory.⁵¹

Concurrent validity will be assessed using Spearman's ρ correlations to compare scores between the *dignity in continence care scales (self-report version)* and the inpatient dignity scale.⁴⁵ Spearman's ρ correlations will also be used to compare scores between the *dignity in continence care scales (staff version)* and the TM-PCC.⁴⁶ We will test the hypothesis of a positive correlation between each of these instruments. Factor validity will be determined using factor analysis. Based on the findings from review of literature in stage 1, either exploratory or confirmatory factor analysis will be conducted to either identify themes covered by the questionnaire or to verify that the items included in the questionnaire fit into at least one of the themes identified from the literature.

The test-retest of the *dignity in continence care scales* (stage 6) will be established using the intraclass correlation coefficient, reported together with its 95% confidence interval. The minimum value of 0.70 will be considered satisfactory.⁴⁹ Stata statistical software version 15 will be used for analyses.

5 | DISCUSSION AND CONCLUSION

Incontinence is a common and distressing symptom that affects most people living in RACFs, many of whom have neurologic conditions such as stroke or dementia. Disability associated with these neurologic conditions increases the risk of being dependent on another person for help to maintain bladder and bowel control or to manage incontinence. It is likely that the way continence care is delivered will affect care recipients' dignity. However, in the absence of an instrument to measure dignity-protective care, there is no quantifiable data about this phenomenon. The instruments to be developed and validated in this study will offer a reliable and valid method to evaluate if

continence care practices protect or diminish the dignity of older people who are care-dependent. They could augment current efforts to improve the overall quality and safety of care for this population, assist in further research about dignity in care, and have broader application across a range of different health and social care contexts.

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ETHICS STATEMENT

Ethics approval was obtained from the Barwon Health Research Ethics, Governance and Integrity (REGI) Unit (Reference 19/38) with reciprocal approval from Deakin University Human Research Ethics Committee (Reference 2019-185).

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