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Feature Article

Testing the reliability and validity of a Transition Map for older adults in long term care settings

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ABSTRACT

Mapping individual patterns of decline in older adults may aid coordinating long term aged care. This study developed a new scale (Transition Maps) to summarise the overall care pathway for long term aged care residents, in a simplified manner incorporating mapping concepts. Transition Maps were developed using mixed methods in two phases, and based on expert opinion, literature review, and input from aged care health professionals. Four professions (primary physician, nurse, allied health, lifestyle services) generated 147 Transition Maps for 38 residents living in a long term care. Preliminary construct validity and inter-rated reliability were evaluated. Results showed that Inter-rater reliability of agreement with the overall care pathway for each resident was kappa = 0.492. Consensus was lowest between nurse care managers and primary physicians (kappa = 0.384), and highest between nurse managers and Lifestyle Services (kappa = 0.77). Preliminary testing of the Transition Map scale provides initial support of construct validity and inter-rater reliability and provides some evidence that Transition Maps can improve the coordination of long term aged care.

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Introduction

Most individuals in developed countries now live relatively healthy lives until a final phase characterised by severe chronic illness and disability that is often prolonged over months or years. With longer life expectancy is an unprecedented increase in dementia¹ and other age-associated illnesses and disabilities, suggesting that new approaches are needed for continued best practice health care. Though the pattern of disability in the last phase of life is shifting, older adults still age in their own individual way. Physiological aging occurs differentially for every older adult, with some organ systems remaining relatively well preserved whilst other systems may be compromised by substantial impairments. For example, some older adults will have predominant brain aging with cognitive disability and altered behavior, whilst others may remain cognitively intact but have various somatic system

impairments resulting in decline in physical function. Some may have both significant somatic concerns and cognitive impairments.

The ability to map individual patterns of health or disability for older adults has utility in aiding medical decisions and coordinating planned care. A number of approaches have been developed – from prognostic estimation models, frameworks based on service need, and illness trajectories. Prognostic estimation models estimate mortality for general patients² or more commonly are limited to specific diseases such as cancer³ and dementia.² However these models have so far demonstrated relatively average performance in estimating mortality.^{2,4} A different mapping approach is based on the complexity of service need rather than illness diagnosis.⁵ This framework outlines three transitional zones that long-term care residents may be identified in: 'living with losses', 'living and dying', and 'dying and death'. Here the actual illness trajectory is secondary to the development of a care approach that is 'reactive, reflective, and responsive'. Though this framework was developed with adequate mixed models methods, no actual tool was developed for use in long term care settings. Illness trajectories^{6–8} are a third approach that map an older adult's progressive chronic illness into one of three groups: (i) no significant functional impairment until a sudden decline in health (e.g. cancer), (ii) a steady deterioration in health interspersed with acute severe exacerbations before sudden death

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(e.g. heart failure, COPD), or (iii) a prolonged progressive health decline starting from a low functional base and ended by a severe acute incidence such as pneumonia (e.g. dementia, frailty). This system suggests that older adults can be categorised into one of only a limited number of illness patterns but the exact number that exist is uncertain^{9,10} as older adults with frailty, organ failure, and cancer have shown significantly heterogeneous trajectory patterns.¹⁰ Still illness trajectories are simpler than prognostic estimation which is difficult for professionals and inaccurate,¹¹ though the utilisation of illness trajectories in a long term care setting is underdeveloped.

Despite limitations with mapping, their principle elements have merit in providing a framework for long term aged care services. As most residents in aged care have multiple illnesses and significant functional decline, formulating and monitoring individual illness trajectories is impractical. However a simpler structured approach to conceptualising trajectories may still be feasible and a simple instrument that incorporates broad health and functional parameters as well as describing trajectories of decline is still needed.

This study developed a new tool (Transition Maps) that could incorporate the common elements of illness trajectories and functional decline seen in long term care settings with the aim of enabling the development of appropriate approaches to care for all residents in aged care. Transition Maps are transparent in broadly articulating resident impairments and overall care approaches, whilst acknowledging the multiple domain changes that an aged care resident may potentially undergo during a series of late life transitions. Though each resident's late life journey is individual, resident-focused goals and health care service efficiencies may be achieved by appropriate 'stratification' of residents onto broadly defined approaches to care. In this study, preliminary scale validity (construct) and reliability (inter-rater) were investigated.

Material and methods

This study was part of a larger project that implemented and evaluated a pilot enhanced model of care in an Australian setting. The enhanced model was developed to address three identified gaps in long term care settings: facilitating multidisciplinary teamwork, transparency of the late-life transitions in health and function of residents, and translation of resident aspirations into achievable goals. The overall aim of the project was to improve person-centered care practice and outcomes as measured by resident satisfaction, quality of life, mood, and goal-attainment. A major component of the enhanced care program was the Transition Map, a scale specifically developed for this program. This paper reports on the first stage of the project in two phases: (1) the development of the Transition Map scale, and (2) preliminary reliability and validity testing of this scale. The second stage of the project included the pilot implementation and evaluation of all components of the enhanced care model in long term aged care facilities and is not discussed further in this paper.

Phase 1: development and validity of the Transition Map Scale

Phase 1 of the study included the initial development of the Transition Map scale. A working group was formed (that included two geriatricians, a long term care nurse practitioner, and a geriatric/gerontology researcher) to define the scope of the new scale (including the goals, setting, context, expertise needed, and level of sophistication of the scale).

A detailed report of the initial content validity of the scale is beyond the scope of this paper, but briefly scale conceptualisation was initially based on the International Classification of Functioning, Disability and Health (ICF; developed as a framework for classifying health using function and disability¹²), as well as international approaches to how long term care is operationalised.¹³ An academic

and gray literature review also suggested that residents in long term care experience substantial transitions along a number of potential care pathways. For example, Froggatt¹⁴ identified transitional states of residents in care, when care staff perceived a resident on a 'downward decline with respect to their state of health', only sometimes attributable to an acute medical event, and accompanied with increasing care staff responsibilities and a change in resident behavior. Estabrooks et al¹⁵ likewise reported that symptom burden increases at end-of-life and identified key policy elements central to end-of-life care, such as avoiding treatments with no prospect of improving quality of life. The working group incorporated these elements for an aged care setting, based on expert opinion, the literature review, and input from aged care health professionals. From this initial content validation process, two dimensions were ultimately identified as central for describing optimally effective and efficient pathways of care using Transition Maps:

- 1) **Illness type:** this dimension categorises a resident's illness very broadly as either a Somatic, Mixed, or Neurocognitive impairment. Somatic illnesses principally include organ-system failures, cancer, and other body related impairments. Neurocognitive impairments are neurological illnesses accompanied with cognitive deficits (predominantly dementia in aged care). The Mixed illnesses are reserved for residents exhibiting both significant somatic and neurocognitive illnesses. These broad terms of somatic or neurocognitive impairment were selected as convenient demarcations appropriate for aged care settings, in part reflecting the distinction between long term care homes in the Netherlands where facilities were defined as somatic or psycho-somatic/psycho-geriatric.¹³
- 2) **Illness severity:** this dimension operationalises the severity of the resident's illness by whether a Restorative, Maintenance or Symptomatic approach to care management is appropriate. Restorative approaches encompass rehabilitation and may involve curative medical interventions and increased allied health support. Maintenance approaches focus care on maintaining function and systems, with implications for reduced allied health interaction. Symptomatic approaches acknowledge that symptoms management is the primary care approach and may include end-of-life/palliative care principles. The Maintenance category was added after the working group pre-tested a draft version of the scale with only restorative and symptomatic categories, and concluded that a substantial amount of information was missing without the inclusion of the maintenance category.

A stratification in two dimensions resulted in nine (3 × 3) potential approaches to care (Fig. 1 and for the blank scale, see Appendix A). Based on feedback from nurse staff, two additional fields were added to the scale as separate tick boxes. One field is ticked to indicate that the resident has a high impact of psychological factors, such as due to substantial behavioral and psychological symptoms of dementia, major depression or anxiety disorder. The other tick box indicates that the resident was assessed as 'unable to be mapped'. This option was provided for when the rater is not sufficiently familiar with the resident to complete the scale, or there are other mitigating factors. Both boxes were incorporated into the scale design just prior to the implementation of the larger study, and are therefore not part of the study results presented here.

Phase 2: reliability and validity testing of the Transition Map Scale

Phase 2 of the study describes preliminary reliability and validity testing that examines the psychometric properties of the Transition Map scale.

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