

## Review Article

# Applications of Minimum Data Set in long-term care research

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## ABSTRACT

Population aging is a global phenomenon that poses special challenges to the health care systems. Advanced aging is often featured by the concurrent progressive declines in both physical and cognitive function, as well as more emotional problems, decreased social engagement, institutionalization and mortality. Although promoting aging in place is the main goal of elderly care, still a certain proportion of older adults need long-term care facilities (LTCFs) admissions. Providing effective management with continuing care services is of critical importance to the overall quality of care. In 1987, under the Omnibus Budget Reconciliation Act, Health Care Financing Administration of the United States started to provide and reimburse long-term care services for older people with complex care needs. To properly financing these services, Minimum Data Set (MDS) was constructed, which included resident assessment instrument, resident assessment protocols and guidelines utilization. MDS worked as a comprehensive, standardized evaluation tool on assessing and managing LTCF residents with different physical, psychological and social conditions. The systematic implementation of MDS substantially improved the quality of LTCF care by identifying the dynamic changes of each item, and understanding the complex intertwined network among each domains. Gradually, MDS became a powerful research resource in addition to its management of long-term care services. This review briefly introduced the development of MDS and related research using MDS, especially the Longitudinal Older VETERans (LOVE) study in Taiwan.

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## INTRODUCTION

Population aging is associated with increased risks of disability, increased care complexity and healthcare utilization, which poses great challenges to the healthcare system and society as well.<sup>1,2</sup> Aging is closely linked to declines in physical function, cognitive function, and decreased social engagements that are of strong adverse impact on disease treatment for older people. According to the report of World Health Organization (WHO), aging speed of Asia is significantly faster than western countries, and so are the burden of care in chronic conditions.<sup>3,4</sup> To prevent adverse health events among older people, the multidisciplinary approach covering functional, medical, and psychosocial domains of older people is of great importance.<sup>5-7</sup> However, the lack of care coordination is a common challenge in caring older people, which may result in inefficient and suboptimal quality of care, fragmentation of care programs and increased assessment burden between facilities and healthcare systems.<sup>1,8</sup>

The Minimum Data Set (MDS) is a comprehensive, standardized evaluation tool on

assessing and managing different aspects of health care issues that the institutionalized elderly in different care settings may encounter.<sup>9</sup> MDS was developed by the Health Care Financing Administration (currently named as Centers for Medicare & Medicaid Services) and endorsed by the United States government after the Omnibus Budget Reconciliation Act (OBRA) in 1987.<sup>9,10</sup> Combinations of the MDS and Resident Assessment Protocols (RAPs) form the major parts of Resident Assessment Instrument (RAI), and the MDS is the core part of the RAI that covers 13 domains with more than 400 items, including functional, cognitive, behavioral, and nutritional status.<sup>2,9,11</sup> The RAI became the foundation of international clinicians and researchers to constructive interRAI network (<http://www.interrai.org>) since 1995 to improve quality of long-term care worldwide.<sup>12,13</sup> This instrument help the facilities in assessing individual's care needs, decision making, development of care plans, and implementation of care plans.<sup>9,12,13</sup> Currently, several MDS modules have been developed to meet various needs in different care settings, such as the long-term care facilities (LTCFs), including MDS- Home Care, MDS- Mental Health, MDS-Acute Care, MDS-Post Acute Care, and MDS-Palliative Care since 1990.<sup>14-18</sup> These MDS instruments were under active employment and were proven to have good detection sensitivity and efficacy for management residents' problems.<sup>1,13,19</sup>

The RAPs are structured, problem-oriented frameworks of MDS information, and examining additional clinically relevant information about an individual.<sup>2,9,11</sup> In total, there are 18 dimensions of RAPs that related to different aspects of care needs, including delirium, cognitive decline/dementia, visual function, communication, ADL/functional rehabilitation, urinary incontinence, psychosocial well-being, mood, behavior, activities, falls, nutrition, feeding tubes, dehydration/fluid maintenance, dental care, pressure ulcers, psychotropic drug use, physical restrain.<sup>9,11</sup> Triggers of RAPs help to identify social, medical and psychological problems of individuals and to guide the direction for care planning. A lot more tools have been developed using items of MDS for some specific conditions, including MDS Changes in Health, End-stage disease, Signs, and Symptoms Scale (MDS CHESS), Activity of Daily Living (ADL) Hierarchy scale, Resource Utilization Group-III for ADL (RUG-III ADL), MDS Cognitive Scale (MDS COGS), Cognitive Performance Scale (CPS), Nursing Home-Confusion Assessment Method (NH-CAM), Depression Rating Scale (DRS), MDS Social Engagement (SocE), and Pain scale.<sup>20-28</sup>

The primary purpose of MDS was to identify resident care problems and the subsequent care plans, but the comprehensive data collection also generate strong research potential in long-term care settings.<sup>29-33</sup> It has been reported that RAP triggers not only identified specific care problems for intervention, but also suggested other closely related RAI aspects for management in a multidisciplinary approach way. In Taiwan, Chinese edition of revised MDS-LTCF was introduced in 2002 and was implanted in some LTCFs as trial tests. Different triggers of Resident

assessment protocols (RAP) help the LTCF staff on decision-making and development of specific care plans for each individual.<sup>1,9,13,19</sup> The Longitudinal Older VETERans (LOVE) study was initiated since 2006 with implementation of this Chinese edition of MDS version 2.1 for the residents living in Veteran Homes in Taiwan. The LOVE team had built up great experiences in Asia on applications of MDS in both care and research.<sup>34-51</sup>

### Resident Assessment Instruments for activities of daily livings

Physical functional decline is a common presentation of aging, and the declining rate may be associated with disease or environmental factors; these complex interrelationship substantially increased the risk of mortality and institutionalization for older adults.<sup>7,29,52,53</sup> MDS ADL Hierarchy scale and RUG-III ADL are two commonly used instruments in assessing physical function of LTCF residents.<sup>20,21</sup> The MDS ADL Hierarchy scale was constructive from items of personal hygiene, toileting, locomotion on unit, and eating. Residents were classified into seven categories as "independent", "supervision", "limited assistance", "extensive assistance grade 1 and 2", "dependence" and "total dependence".<sup>20</sup> The MDS RUG-III ADL was developed from items of bed mobility, transfer, toilet use and eating with a total score from 4 (completely independent) to 18 (completely dependent). Physical dependence was identified by higher RUG-III ADL score and showed a worsening status as the score increases.<sup>21</sup> Previous MDS studies of each individual RAI items had revealed that residents with more ADL dependence may also have more complex co-morbidities, cognitive impairment, urinary incontinence, malnutrition, vision problems and risks for falls, hip fracture, pressure ulcers and dual use of dual use of anticholinergics and cholinesterase inhibitors.<sup>29,54-56</sup> The LOVE study and other longitudinal cohort studies reported that poor ADL status is positively associated with higher prevalence of urinary incontinence, higher fall risk and fear of fall, more rehabilitation needs, more frequent emergency department visiting, longer hospital stay, and higher mortality rate.<sup>34-39,57-60</sup> Other than aiming at improving balance and continence, adequate nutritional supplement, cognitive function enhancement and caring burden of each facility are of the same importance for prevent ADL decline or further improvement.<sup>9,32,40,51,61</sup>

### Resident Assessment Instruments for cognitive decline/dementia

Dementia is a syndrome caused by neurodegenerative disorders that presents progressive deterioration of memory, mentality and physical independence, and the prevalence of dementia doubles every 5 years over the age of 65.<sup>5,62</sup> Dependency, disability and great burden to families and societies resulted from dementia have made dementia ranked second in burden of chronic condition care as the global health priority by the WHO.<sup>5</sup> Due to physician's misperception and social stigma, the diagnosis of dementia is lower than expected, which also limits the possibility of

further survey and intervention for dementia.<sup>5,63,64</sup>

Two reconstructed tools from MDS are commonly used for early detection of dementia and for evaluation of dementia severity, including CPS and MDS COGS.<sup>22,23</sup> The CPS was generated from items for comatose consciousness, severely impaired physical function, decision making, make oneself understood, and short-term memory. Residents were classified into seven categories of cognitive function, such as “intact”, “borderline intact”, “mild impairment”, “moderate impairment”, “moderate-severe impairment”, “severe impairment” and “very severe impairment.”<sup>22</sup> The MDS COGS was constructed from 8 items for cognitive patterns, communication patterns and physical functioning, which classified all residents into 4 categories of cognitive status including “intact-mild impairment”, “mild-moderate impairment”, “moderate-severe impairment” and “severe-very severe impairment.”<sup>23</sup> Both CPS and MDS COGS were proven as efficient as Mini-Mental Status Evaluation, and both showed good validity on dementia detection in facilities.<sup>41,65-69</sup> In LOVE study, the prevalence of dementia assessed by either CPS or MDS COGS was compatible with that screened by MMSE, and were also similar to the age-specific prevalence of WHO report.<sup>5,35,41</sup> Better cognitive function was associated with higher serum levels of vitamin B12, better ADL independence, more rehabilitation potential, less frequent urinary incontinence, less physical and chemical restraints in facilities, less hip fractures, and more surviving benefits.<sup>26,32,34,36,40,47,54,59,70-74</sup> By using MDS, it is more possible to achieve the goal of WHO to early detect dementia in LTCFs and to further enable the care staff to take multidisciplinary approach for timely care of dementia.

### Resident Assessment Instruments for delirium

Delirium is common problems among LTCF residents, presenting with symptoms of acute cognitive change, altered consciousness and fluctuating course of inattention.<sup>75</sup> Approximately 15-24% LTCF residents had symptoms suggestive of delirium, especially in the first week after admissions.<sup>76-78</sup> Delirium was associated with greater risk of functional decline, cognitive impairment, morbidity and mortality, but it was usually underdiagnosed due to fluctuating presentation of symptoms.<sup>28,79</sup> The RAP trigger for delirium was often ignored because suboptimal specificity, so the NH-CAM was developed to improve specificity without loss of sensitivity.<sup>11</sup> The NH-CAM was an extension of RAP trigger to mimic the criteria of Confusion Assessment Method, including nine items for mental function variation, mood decline, cognitive decline, behavior decline, inattention, altered perception/awareness, restless, lethargy, and disorganized speech.<sup>28,80</sup> It categorized residents into three classes of delirium, such as “full delirium”, “Level 1 subsyndromal delirium (SS-1)” and “Level 2 subsyndromal delirium (SS-2),” respectively.<sup>28</sup> The estimated percentage of delirium among residents was 30.4-39.7% for subsyndromal delirium and 1.4-6.5% for full delirium.<sup>28,81</sup> In cross-sectional studies, delirium was related to cognitive impairment, rejection of care behaviors,

and depressive symptoms.<sup>81,82</sup> More severe delirium was associated with higher risk of aspiration pneumonia, lower functional recovery, higher mortality and re-hospitalization rate, while worsening of delirium was possibly caused by physical restraints and cognitive dysfunction.<sup>28,30,78,83</sup>

### Resident Assessment Instruments for social engagement and depression

Social engagement is the ability to initiate social interaction and to be receptive to social overtures from others, including the formation of social ties, contact, and interactions. Nowadays, social engagement has attracted extensive research interest for its strong influences on functional impairment, cognitive decline, as well as depressive mood, and there was complex intertwined network between social engagement, depression, co-morbidities, ADL function and cognitive status.<sup>50,84,85</sup> Social isolation rather than loneliness was considered as the factor for functional decline, emotional stress and mortality.<sup>86-88</sup> The MDS SocE is derived from 6 MDS items scored dichotomously as positive versus absent, with the sum ranged 0 to 6. Higher MDS SocE score indicated better interaction with the others and better quality of life.<sup>24</sup>

A total of 16 mood indicators for verbal and non-verbal distress in MDS completed the MDS DRS, which was compatible with the 17-item Hamilton Depression Rating Scale and 19-item Cornell Scale for Depression.<sup>27</sup> Although the sensitivity and specificity of DRS were challenged, DRS remained effective in detecting depressive symptoms and associated factors among LTCF residents.<sup>43,67,89-94</sup> The social engagement was influenced by hearing problems, pain control, urinary incontinence, physical restraint, cognitive function, and depression, and residents with better social engagement were found to lower mortality risk.<sup>50,87,95-102</sup> Depressive symptoms also interacted with somatic discomforts, ADL performance, cognitive status, social engagement and underlying diseases, and was found to have positive association with weight loss.<sup>50,102-111</sup>

### Minimum Data Set Changes in Health, End-stage disease, Signs, and Symptoms Scale (MDS CHESS) and sum of Resident Assessment Protocol triggers

Co-morbidity has strong impact on health of older people, but measurement of the severity and status of co-morbidity is always challenging. Charlson's co-morbid index was developed to quantify the disease burden, but it showed little changes in serial assessments in LTCFs because of the lack of certain disease entities.<sup>112</sup> The MDS CHESS and the sum of PAP triggers were proposed to assess residents' health status among LTCF residents, and the efficacy had been shown in previous studies.<sup>26,48</sup> The MDS CHESS included items for changes of decision making, ADL status, health condition of vomiting, peripheral edema, dyspnea, end-stage disease, signs and symptoms of body weight loss and fluid status.<sup>26</sup> The MDS CHESS showed a good predictive value for falls, emergent services utilization, and mortality, and it was associated with physical activity,

complex medical procedures and pain.<sup>26,59,60,113</sup> On the other hand, using the sum of RAP triggers to estimate the burden of care was firstly proposed by the LOVE study, which was shown to be an important indicator for increased care needs, care complexity and more severe co-morbidities among LTCF residents. With more sum of RAP triggers, the residents had more health adverse outcomes, such as physical functional decline and death after adjusted for age and co-morbidities.<sup>48,49</sup>

### Quality indicator in Resident Assessment Instruments

Quality indicators (QI) are important for LTCF managers to evaluate the overall quality of care, and to identify existing unmet care needs.<sup>114</sup> Weight loss and poor nutrition were two important QIs on measuring the quality of care since 1987, and more indicators were added for improving the facilities daily practices on managing residents' needs.<sup>2,115</sup> The MDS-QIs were retrieved from 24 items of 14 categories for accidents, behavior/emotional problems, clinical management, cognitive patterns, elimination continence, infection control, nutrition, physical function, psychotropic drug use, quality of life, sensory function/communication, and skin care.<sup>114</sup> The MDS-QIs assisted the LTCFs to develop attitudes of person-centered care, to prevent interactive indicators risks, and to improve residents' health outcome.<sup>116-122</sup> It also guides the government to have a clear view of the need of each facility and to offer necessary support.<sup>122-125</sup>

### Other Resident Assessment Instruments and major limitations

Focused on specific RAP trigger, many studies reported interventions more than the problem itself. RAP trigger for urinary incontinence was found associated with poor quality of life, increase in ADL dependence and cognitive impairment by longitudinal cohort studies.<sup>58,99,126,127</sup> Cross-sectional studies revealed that RAP trigger for urinary incontinence was associated with older age, more frailty, poorer physical function, more cognitive impairment, and more frequent hospitalization, higher risks for urinary tract infection, pressure ulcers and depression.<sup>36,58,128</sup> Anorexia, a risk factor of morality, was associated with potentially reversible RAP triggers for mood, dental care, and psychotropic drug use.<sup>129</sup> The RAP trigger for pressure ulcer were related to increased ADL and diabetes mellitus diagnosis.<sup>130</sup>

However, inter-rater variations, low sensitivity in detection rate, low reproducibility and validity were all reported challenges in using RAP triggers.<sup>1,11,73,131-133</sup> Currently, studies on the RAPs for urinary incontinence and pressure ulcer showed better validity and low inter-rater variation for problems detection.<sup>132,134-136</sup> However, the RAP triggers for nutrition, feeding tubes dehydration/fluid maintenance and dental care may not precisely represent the prevalence and risks of undernutrition among residents.<sup>115,131</sup> Moreover, the RAP trigger of pain had low detection sensitivity and great heterogeneity of pain severity among different facilities.<sup>137,138</sup>

### CONCLUSIONS

The MDS offers a comprehensive evaluation for older adults in different care settings, and identifies care needs on physical, cognitive, social and environmental dimensions, and care planning. These data also generate strong research interests to improve quality of care and to management of services. Experiences of LOVE study in Taiwan clearly demonstrated the excellence of using MDS for care management and research.

### CONFLICTS OF INTEREST STATEMENT

Conflicts of interest: none declared. Funding resource: none.

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