2021-08-16

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Hoben, M

http://hdl.handle.net/10026.1/18578

Original Study

Feasibility of Routine Quality of Life Measurement for People Living With Dementia in Long-Term Care

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A B S T R A C T

Keywords:
Quality of life
dementia
feasibility
long-term care
measurement
DEMQOL-CH

Objectives: Maximizing quality of life (QoL) is the ultimate goal of long-term dementia care. However, routine QoL measurement is rare in nursing home (NH) and assisted living (AL) facilities. Routine QoL measurement might lead to improvements in resident QoL. Our objective was to assess the feasibility of using DEMQOL-CH, completed by long-term care staff in video calls with researchers, to assess health-related quality of life (HrQoL) of NH and AL residents with dementia or other cognitive impairment.
Design: Cross-sectional study.
Setting and Participants: We included a convenience sample of 5 NHs and 5 AL facilities in the Canadian province of Alberta. Forty-two care staff who had worked in the facility for ≥3 months completed DEMQOL-CH assessments of 183 residents who had lived in the facility for 3 months or more and were aged ≥65 years. Sixteen residents were assessed independently by 2 care staff to assess inter-rater reliability.
Methods: We assessed HrQoL in people with dementia or other cognitive impairment using DEMQOL-CH, and assessed time to complete, inter-rater reliability, internal consistency reliability, and care staff ratings of feasibility of completing the DEMQOL-CH.
Results: Average time to complete DEMQOL-CH was <5 minutes. Staff characteristics were not associated with time to complete or DEMQOL-CH scores. Inter-rater reliability [0.735, 95% confidence interval (CI): 0.712-0.780] and internal consistency reliability (0.834, 95% CI: 0.779-0.864) were high. The DEMQOL-CH score varied across residents (mean = 84.8, standard deviation = 11.20, 95% CI: 83.2-86.4). Care aides and managers rated use of the DEMQOL-CH as highly feasible, acceptable, and valuable.
Conclusions and Implications: This study provides a proof of concept that DEMQOL-CH can be used to assess HrQoL in NH and AL residents and provides initial indications of feasibility and resources required. DEMQOL-CH may be used to support actions to improve the QoL of residents.

Maximizing quality of life (QoL)—that is, a person's perceived physical, emotional, and social well-being—is the ultimate goal of dementia care.[1] The majority of long-stay nursing home (NH) residents (100 days or longer) have dementia (60% in the United States,[2] 70% in Canada,[3] and the United Kingdom[4]). An additional 10% to 20% have significant cognitive impairment, and many with dementia are not diagnosed as such.[2–5] Dementia rates in assisted living (AL) are also as high as 60%.[6,7] People living with dementia in NHs or AL have poorer QoL than those in the community.[8] The quality of NH care has been extensively studied and is routinely measured using indicators like proportions of people who experience pressure ulcers and falls.[9] Although an important determinate of QoL, quality of care measures are more narrow and ignore QoL issues like social interactions and sense of purpose, and they focus on impairments rather than the resident's subjective reaction to specific health issues.[10]

The World Health Organization defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[11(p1405)] This definition highlights that an individual's self-perception is the key feature of QoL. Health-related QoL (HrQoL) describes how an individual perceives the impact of a *health condition* on their lives.[12] These definitions have systematically guided the development of the DEMQOL suite of instruments[13]—a set of questionnaires to measure HRQoL in people with dementia or other cognitive impairment. In this article, we will focus on DEMQOL-CH, a proxy assessment of HrQoL to be completed by care home residents' direct care staff.[14]

Routine measurement of dementia-specific HrQoL in NHs or AL is rare and has been an enduring challenge.[15] This is a major gap since direct information on resident HrQoL could be a powerful instrument in developing individual and care home level action plans to improve HrQoL outcomes at an individual and aggregate level.[14] Because QoL is essentially subjective, a person's self-report is the preferred way of assessing QoL.[16] The large majority of people with mild to moderate dementia can self-report their QoL with acceptable validity and reliability.[17] However, residents with more severe cognitive impairment very often have difficulties self-reporting their QoL, and studies requiring resident QoL self-reports[18–20] exclude up to 30% of all residents (those with a Cognitive Performance Scale[21,22] score of 3 or more).[23] Proxy reports of HrQoL have therefore been developed to ensure that those with severe dementia can be included in evaluations. For those in NHs and AL, the choice of proxy is between family/friends and care staff. Unfortunately, not all residents have family/friend proxies, amounting to up to 35% of residents in some Canadian NHs.[24] Therefore, if a single measurement is needed across severities of cognitive impairment and family support, staff proxy assessments may be the only consistent source available to assess QoL.

There are situations where there are potential benefits to obtaining care staff proxy reports of resident QoL. These include (1) when the resident "voice" is wanted but because of dementia severity they cannot self-report (even if it comes with the extra error inherent in the use of a proxy); (2) where staff proxy reports are in addition to resident self-reports and/or family or friend proxy reports to assess how staff perceptions of resident QoL influence how they deliver care[25]; (3) in longitudinal studies where dementia progresses (residents move from being able to self-report to not); (4) situations where researchers and family and friend proxies cannot access residents to obtain self-reports (as was the case during the COVID-19 pandemic); and (5) when there is a need for a pragmatic system to allow the collection of the same data on the whole population to compare QoL across residents with different levels of cognitive impairments, generating symmetric data on those who can and cannot self-report.

Generating a mixture of self- and proxy reports of QoL for different residents compromises comparability since proxy-reports are consistently lower than self-reports, and staff and family proxy reports also differ systematically.[26] Therefore, simple QoL proxy assessment is a promising approach that can be validly and reliably completed by direct care staff to give a common metric for residents across dementia severity and measure resident QoL scores over time.[14] Care aides (nursing assistants) are in the unique position of having, through their care contact, the detailed knowledge about residents that is required for valid QoL assessment.[14] They provide 90% of direct care and are the only care providers with residents for extended times each shift. In making responses, they can include QoL-related self-reports from residents who can verbally express their needs, and interactions with residents' families as well as their observation of residents' nonverbal cues.

In the United States, Minnesota routinely measures QoL in NH residents,[27] using a tool developed and validated in a study commissioned by the Centers for Medicare & Medicaid Services.[28] Trained interviewers conduct face-to-face interviews with a sample of residents in each home.[29] Other US states, such as Ohio[30] and Maryland,[31] routinely ask residents' family/friend care partners about their satisfaction with factors that may affect the resident's life in the facility (eg, activities or food). Also, the routinely collected Minimum Data Set 3.0 assesses resident self-reports or care staff ratings (if residents cannot self-report) of resident preferences for customary routine activities.[32] However, factors potentially *influencing* QoL (someone's satisfaction and preferences) are not *actual measures* of QoL (the perceived impact of these factors on an individual's life), and the training, time, and cost needed to implement routine measurement systems such as Dementia Care Mapping[33] or the Minnesota system[28] are major barriers to routine, systematic QoL assessment.

In response to these challenges, we developed DEMQOL-CH,[14] designed for all residents in NHs with dementia or other cognitive impairment, which could be completed quickly and with minimal care staff resources.[14] Here, we report the results of the first large-scale evaluation to assess the feasibility of routine use of this system.

Methods

Research Design

This was a cross-sectional feasibility study, including a subsample of residents assessed a second time after 3 months.

Ethics Approval

The research protocol was approved by the University of Alberta Ethics board (Pro00096355), verbal consent to participate was obtained from all care aides and managers. Researchers were not aware of resident names or other identifying details at any time (details in data collection section). Therefore, resident consent was not required.

Stakeholder Involvement

In this program, we engaged with key stakeholders (health care policy and system decision makers, representatives from care organizations, people with dementia, and their family or friend caregivers) nonhierarchically at all stages of the research process. Key decisions on the design of the approach reported here were made on October 9, 2019, in a policy forum attended by representatives of all stakeholder groups in the Canadian province of Alberta.[34] These key decisions included (1) the use of the DEMQOL-CH completed by direct care staff in this study; (2) the focus on NHs and AL; and (3) identification of key outcomes to be assessed [time to complete, care staff and manager rated feasibility and acceptability, inter-rater reliability (IRR), internal consistency reliability]. At that forum, key provincial policy makers identified an intention to work toward establishing routine dementia-

specific assessment of HrQoL in NHs, using DEMQOL-CH informed by this research.

DEMQOL-CH

DEMQOL-CH (Supplementary Material 1) was developed from the widely used DEMQOL system.[26] DEMQOL-Proxy has been validated extensively.[35,36] However, the researchers found that it did not perform well when completed by care aides without an interviewer.[14] Therefore, they modified DEMQOL-Proxy into DEMQOL-CH,[14] with the same 31 items but with instructions and items modified for self-completion by care aides. The tool assesses dementia-specific HrQoL by summing scores of 31 items rated on a 4-point scale (overall score 31-124, where higher is better). We chose DEMQOL-CH because it is brief, has good psychometrics, and is designed to work across dementia severity. It is completed by direct care staff (mostly care aides), minimizing resident burden and cost to facilities and the system, and does not require external assessors. Although proxy reports of QoL are consistently lower than self-reports,[37] they measure the same construct as suggested by factor analyses. As noted above, DEMQOL-CH has advantages in long-term care where self-report is often impossible because of dementia severity and residents may not have a family or friend carer to provide proxy assessment.[38] The UK development study[14] reported that DEMQOL-CH scores completed by care aides correlated well with Dementia Care Mapping (an established, but time-consuming, observational method to assess resident QoL)[33] and did not differ statistically significantly from DEMQOL-Proxy scores, obtained by research assistants interviewing care aides. Internal consistency reliability (0.90) and test-retest reliability were high (0.72) and IRR satisfactory (0.40).

Setting

We recruited a convenience sample of 5 NHs and 5 AL facilities in Alberta. Alberta offers 4 levels of AL: (1) Supportive Living, which is not privately subsidized and provides the lowest levels of care, and (2) 3 levels of publicly subsidized Designated Supportive Living (DSL3, 4, and 4D). DSL4D settings provide specialized dementia care. We included DSL3, 4, and 4D settings. Because of COVID-19, site visits were not possible, and we could not obtain direct resident consent. We therefore only collected care staff ratings of resident QoL.

Sample

We asked 1 key contact in each facility (usually a director of care or care manager) to select eligible residents for assessment. Residents had to be 65 years or older and have a CPS score of 2 (mild cognitive impairment) or higher. To ensure care staff knew residents well, residents had to have lived in the facility for 3 months or longer. Facilities were eager to participate and to learn about their residents' QoL. However, staff had very limited time available. Therefore, we negotiated with each facility individually how many residents they were able to assess. We asked key contacts to select an equal proportion of residents with mild (CPS score of 2), moderate (CPS score of 3 or 4), and severe (CPS score of 5 or 6) cognitive impairment. We also asked key contacts to only include residents for whom a care staff member was available who knew the resident well. To ensure this, care staff had to have worked in the facility for 3 months or longer and cared for the resident on at least 3 shifts during the week before the assessment (because the DEMQOL-CH asks about the last 7 days). Often, residents were cared for by care staff who had not worked in the facility for 3 months or longer, or residents had different care staff look after them every day in the week before the assessment. These residents were excluded.

Data Collection

No identifying resident details were shared with the research team. For each facility, we generated a list of random resident IDs with blank lines next to the IDs, which we shared with our key contact. The key contact added names of selected residents to the list but did not share that list with researchers. In video calls, research assistants shared the DEMQOL-CH with staff via screen sharing and recorded care staff responses, time to complete, and care staff ratings of feasibility, acceptability, and demographics. Research assistants and care staff only used the random resident IDs to refer to residents, and random IDs enabled us to conduct repeated DEMQOL-CH assessments on the same resident. Assessments were completed between August 2020 and January 2021. A subsample (n = 16) was independently assessed by 2 care aides within 24 hours to evaluate IRR. In terms of sample size, with $\alpha = 0.05$, $\beta = 0.2$, and $\rho_0 = 0$ (ie, null hypothesis assuming IRR = 0), a sample of 14 residents was required to detect an assumed IRR (ρ_1) of 0.6.[39] Furthermore, with $\alpha = 0.05$ and $\beta = 0.2$, to detect an internal consistency reliability effect of 0.9 [95% confidence interval (CI) ± 0.05] in a tool with 30 items, a sample size of 171 participants was required.[39]

Outcomes and Statistical Analyses

Analyses were performed using SAS, version 9.4 (SAS Institute, Inc., Cary, NC). We descriptively assessed means [standard deviations (SDs)] and medians (interquartile ranges) of continuous outcomes (time to complete, DEMQOL-CH item and overall scores), and frequencies (proportions) of categorical variables (participant demographics, facility characteristics, feasibility ratings). We used repeated measures mixed models to assess responsiveness to change of DEMQOL-CH scores. To assess IRR, we estimated the intracluster correlation of the overall DEMQOL-CH score obtained from different care aides on the same resident, using hierarchical mixed models with a resident-level random intercept. Finally, we assessed whether care aide characteristics (age, sex, job experience, speaking English as first or additional language) were associated with variations in time to complete and whether care aide and facility characteristics (NH vs AL, for-profit vs not-for-profit ownership, bed size) were associated with the overall score, using hierarchical mixed models with random intercepts to account for dependencies of assessments obtained from the same care aide.

Results

We present characteristics of included facilities and care staff in Tables 1 and 2. Dementia rates in our sample ranged from 40% to 100% per facility (mean = 66%, SD = 18%). Dementia rates in NHs were slightly higher (71% ± 12%, ranging from 50% to 85%) than in AL (61% ± 21%, ranging from 40% to 100%), but 1 AL home only admitted people with dementia. Forty-two care staff (21 in each, NHs and AL) completed DEMQOL-CH assessments on 183 residents [82 (44.3%) in NHs, 101 (55.7%) in AL]. Sixteen (8.7%) were included in the IRR evaluation. There were no missing responses for staff survey, facility survey, and DEMQOL-CH items. Completion time was low (mean = 4.67 minutes, SD = 1.53, 95% CI: 4.48-4.85, median = 4.23 minutes, interquartile range: 3.72-5.12). Two-thirds of the variance in time to complete was explained by the individual who completed it (intracluster correlation = 0.665, 95% CI: 0.595-0.760); no other staff characteristics were associated with completion time.

The average DEMQOL-CH score was 84.8 (SD = 11.20, 95% CI: 83.2-86.4). Both the IRR (intracluster correlation = 0.735, 95% CI: 0.712-0.780) and the internal consistency reliability (Cronbach's α = 0.834, 95% CI: 0.779-0.864) were acceptable.

Table 1
Number of Study Participants by Facility

Facility No.	Type	FP/NP	Dementia Rate	No. of Beds	Residents Assessed, n (%)	Participating Care Staff, n
01	NH	NP		100	25 (25)	5
02	NH	FP		148	20 (14)	5
08	NH	NP		400	15 (4)	2
09	NH	NP		116	16 (14)	3
10	NH	NP		210	6 (3)	6
03	AL	FP		74	31 (42)	3
04	AL	FP		200	20 (10)	2
05	AL	FP		163	26 (16)	13
06	AL	FP		161	18 (11)	2
17	AL	NP		36	6 (17)	1

FP, for-profit; NP, not-for-profit.

Staff characteristics were not associated with DEMQOL-CH score, and we found no clustering of scores within care staff. DEMQOL-CH scores did not differ between NH and AL settings or by bed size. However, the average QoL was lower in for-profit, compared to not-for-profit, facilities ($\beta = -12.21$, 95% CI: -21.95, -2.47, $P = .014$). Care staff and key contacts rated DEMQOL-CH as highly feasible and acceptable for use in routine practice (Table 3).

Discussion

This is the first large-scale evaluation of the DEMQOL-CH. We found it was feasible for care staff to assess HrQoL of residents living with dementia or other cognitive impairment in NH and AL settings using this tool, even under pandemic conditions. The resources required were minimal, with a completion time of less than 5 minutes per assessment and no licensing costs for using DEMQOL-CH. Internal consistency reliability and IRR were high, and scores were independent of characteristics of the person completing the assessment. These data are not definitive. Further work is needed including more representative samples of NHs, AL facilities, and residents. However, these data provide an encouraging demonstration of proof of concept.

We found a higher IRR (0.74) than reported in the UK study (0.40).[14] This may be because we asked key contacts to select 2 care staff members who both knew the resident well for IRR assessments—an important consideration going forward. The average DEMQOL-CH score in our sample (86.1, SD = 11.10) was lower than in the United Kingdom (98.8, SD = 12.36).[14] COVID-19 control measures, like family visiting restrictions and reduced social engagement with staff, may have negatively affected resident HrQoL.[40] However, with no prepandemic HrQoL data available, the impact of these measures on resident HrQoL cannot be determined, highlighting the potential value of routinely monitoring resident HrQoL.

Our study was not powered for between-group comparisons, but the finding that dementia-specific HrQoL in for-profit facilities was lower than in not-for-profit facilities is in line with the available literature.[8] However, in contrast to our study, US-based studies have found higher QoL among AL residents, compared with NH residents.[8,41,42] Care needs of AL residents in the Canadian province of Alberta have become increasingly complex in the last decade, approaching those of NH residents.[6,43] Alberta has implemented aggressive aging in place policies, reserving NH beds for those with the most complex care needs, increasing the number of publicly funded AL beds, and differentiating AL options into 4 levels,

Table 2
Care Facility and Care Staff Characteristics

	Total	NHs	AL
Care facility characteristics			
Number of facilities	10	5	5
Ownership			
Public or voluntary not for profit	5 (50)	4 (80)	1 (20)
Private for profit	5 (50)	1 (20)	4 (80)
Size			
Small (<80 beds)	2 (20)	0 (0)	2 (40)
Medium (80-120 beds)	2 (20)	2 (40)	0 (0)
Large (>120 beds)	6 (60)	3 (60)	3 (60)
Care staff characteristics			
Number of care staff	42	21	21
Role			
Care aide	32 (76)	17 (81)	15 (71)
Licensed practical nurse	5 (12)	4 (19)	1 (5)
Other	5 (12)	0 (0)	5 (24)
Age category			
≤30 y	6 (14)	1 (5)	5 (24)
31-40 y	14 (33)	8 (38)	6 (29)
41-50 y	12 (29)	7 (33)	5 (24)
>50 y	10 (24)	5 (24)	5 (24)
Females	39 (93)	19 ()	20 (95)
Highest education			
Diploma, certificate, high school diploma	25 (60)	16 (76)	9 (43)
Bachelors or master's degree	17 (40)	5 (24)	12 (57)
English as additional language	27 (64)	10 (48)	17 (81)
Years of job experience, mean (SD)	8.4 (7.1)	12.0 (8.2)	4.8 (2.7)

Unless otherwise noted, values are n (%).

Table 3
Care Staff and Key Contact Ratings of Feasibility and Acceptability of the DEMQOL-CH

Question	Care Staff, n (%) (n = 14)	Key Contacts, n (%) (n = 9)
Easy or very easy to help us organize the DEMQOL-CH data collections	—	6 (67)
Agree or strongly agree that time to complete the DEMQOL-CH is acceptable	—	7 (79)
Easy or very easy to understand the DEMQOL-CH questions and instructions	14 (100)	—
Easy or very easy to answer the questions	11 (79)	—
Agree or strongly agree that questions about residents' feeling are relevant to participant's care practice	14 (100)	7 (79)
Agree or strongly agree that questions about residents' worries related to their memory are relevant to participant's care practice	14 (100)	7 (79)
Agree or strongly agree that questions about residents' worries related to their daily life are relevant to participant's care practice	14 (100)	8 (89)
Agree or strongly agree that information about a resident's QoL, assessed by this questionnaire, is valuable	14 (100)	7 (78)

depending on residents' care needs.[44] We only included publicly subsidized AL settings designated to residents with higher care needs. This may be a possible reason why we did not find a difference in dementia-specific HrQoL between AL and NH residents.

Study Limitations

First, it was conducted during the COVID-19 pandemic, preventing us from going on site to collect clinical data from residents with dementia to better understand the sample. We have a further study in the field, currently collecting DEMQOL-CH data from close to 700 residents in 10 NHs and linking their HrQoL data to their routinely collected clinical data. This will enable us to assess factors associated with resident dementia-specific HrQoL and to further assess validity of the DEMQOL-CH.

Second, we used a convenience sample of facilities, and staff and residents were selected by the care facilities. This design limits generalizability. Key contacts were required to determine eligibility of residents and staff, and this likely introduced selection bias. Therefore, we designed this study as a feasibility and proof of concept study, rather than to being in any way definitive. While supportive and interested in our study, facilities often had limited capacity and could only afford limited amounts of staff time to conduct DEMQOL-CH assessments. Therefore, we were not able to assess all eligible residents or staff, and neither could we collect data on the number of care staff who were ineligible or refused to participate. However, we encouraged facilities to include residents with various levels of cognitive impairment. The fact that even in times of a pandemic facilities were willing to dedicate staff resources to learn about their residents' HrQoL suggests that our approach is of interest to these sites. This study is an early step in the development of an evidence base. We have started with residents from whom we could obtain data in a pandemic, by involving care aides. The next stages of our work will include resident self-reports, as well as DEMQOL-CH, and will relate those assessed to the whole resident population. We plan to develop explicit and operationalized criteria about the amount of time that care aides need to have spent with the resident to be able to complete the measure. we will also develop guidance on what to do if there is no one available who can do this. It is possible that the data on feasibility, the data quality and completeness, and the time taken to complete will be different when we work with more generalizable and representative samples of staff and residents.

Third, staff and key contact assessments of DEMQOL-CH feasibility and acceptability may include response bias. Staff participants agreed to participate in the study, were aware of the study question, and may have responded in a way they thought was desirable by the researchers. However, we used electronic, anonymous rating surveys self-completed by care staff to minimize this bias.

Fourth, unlike the MDS, the DEMQOL-CH does not provide detailed instructions on the observation of residents (ie, who

should do it, how to do it, what sources of information should be considered, etc). Therefore, care aides will have seen residents for varying amounts of time in different situations and at different times of the day. We tried to minimize this heterogeneity by excluding care aides and residents who had not been in the facility for at least 3 months and residents who did not have a care aide who cared for them on at least 3 shifts during the 7 days before the DEMQOL-CH assessment.

Inter-rater reliability was acceptable, suggesting good agreement of DEMQOL-CH scores among independent raters. However, more detailed operationalized instructions will be essential for future uses of the DEMQOL-CH. We are currently conducting cognitive interviews with care aides to assess how well care aides know the residents they assess and how they interpret the DEMQOL-CH instructions, items, and scale. This will inform additional instructions to mitigate and minimize heterogeneity of using and interpreting the DEMQOL-CH among care aides and, if needed, we will revise the wording of problematic items.

Conclusions and Implications

This study presents critical data on an early step in establishing a feasible, valid, routine system of HrQoL assessment for people with dementia or other cognitive impairment living in NH and AL facilities. Directly measuring HrQoL in people with dementia or other cognitive impairment living in these settings has potential to maintain and improve HrQoL, informing care planning at an individual level and intervention at a facility level. This study provides a proof of concept that care staff can assess dementia-specific HrQoL using a quick, simple instrument with minimal specialist support. We now need to test this in representative populations of NHs and AL facilities, staff, and residents and develop systems that will enable dementia-specific HrQoL data to be collected routinely and regularly over time to inform individual-level care planning and enable person-centered care that enhances resident HrQoL. When aggregated, these data would provide powerful evidence with which to monitor and improve the quality of services provided for people living with dementia or other cognitive impairment in NH or AL facilities.

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