

# Dementia, pain, depression, behavioral disturbances, and ADLs: toward a comprehensive conceptualization of quality of life in long-term care

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## SUMMARY

**Objectives** Quality of life in long-term care settings is a multidimensional construct that includes functional, cognitive, behavioral, and psychological variables. Quality of life variables have been found to be related to one another, but directional influences have not been tested.

**Methods** The purpose of this study was to develop and compare two competing path models composed of quality of life variables, including dementia, pain, behavioral disturbances, and ADLs.

**Results** Path analytic results revealed that cognitive, emotional, and behavioral variables interact with one another to predict patients' activities of daily living. Pain levels did not influence activities of daily living directly, but rather influenced behavioral disturbances and depression, which in turn influenced activities of daily living.

**Conclusions** These preliminary findings suggest that in order to assist long-term care residents in improving their activities of daily living, decreasing pain is likely to yield the greatest overall improvements. Future research on the relationships between quality of life variables is recommended to further develop multidimensional treatment models for healthcare providers in long-term care. Copyright © 2004 John Wiley & Sons, Ltd.

KEY WORDS—quality of life; long-term care; pain; elderly

Variables composing quality of life are routinely assessed in long-term care settings in order to track the status of the resident and the effectiveness of care. Spitzer (1987) defined quality of life (QOL) as a concept that involves physical, social and psychological functioning and well-being. In the context of elderly persons with dementia, Whitehouse *et al.* (1997) defined QOL as involving cognitive functioning, activities of daily living, social interaction, and psychological well-being. As such, the strict biomedical notion of QOL has given way to a multifaceted construct that involves functional, cognitive, social, and psychological components.

There are many variables that are postulated to contribute to (or conversely, hinder) QOL in long-term care (LTC). Recently a group of clinical geropsychologists targeted the following variables as targets for assessment and treatment: cognitive impairment, emotional distress, behavioral disturbances, and functional assessment (Lichtenberg *et al.*, 1998). Kunik and colleagues (2003) designed a theoretical model composed of variables that predict behavioral disturbances in LTC. Resident characteristics, such as illnesses, gender, SES, genetics, psychological disturbances, and dementia were hypothesized to predict behavioral disturbances among LTC residents. These variables are also considered to be important individual factors to assess and treat in the younger rehabilitation population (Mayer and Gatchel, 1988; Flor *et al.*, 1992; Turk, 1996; Okifuji *et al.*, 1999).

The relationships between the cognitive, social, psychological, and functional components of QOL have been studied in LTC using certain self-report

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instruments and clinical rating scales. Nagamoto *et al.* (1997) investigated the relationship between QOL (defined as morale and general sense of well-being), cognitive impairment, depression, behavioral disturbances, and activities of daily living. Their findings suggested that depression was significantly correlated with QOL, but cognitive impairment, behavioral disturbances, and activities of daily living were *not* significantly correlated with QOL. The authors hypothesized that cognitive impairment, although not having a direct link to QOL, is likely to be mediated by behavioral disturbances.

Gonzalez-Salvador *et al.* (2000) studied the relationships between QOL (as measured by instruments assessing social relationships, distressful behaviors, and activities of daily living), cognitive impairment, severe functional impairment, orientation, physical symptoms, and depression. The researchers found that all of these variables were significantly intercorrelated with one another.

Pain is a variable that is consistently missing from the various contemporary definitions of QOL. Although research on pain and its correlates to QOL in LTC is lacking, the prevalence of pain among the elderly has been estimated to be as much as three times as high than among the younger adult populations—40% to 85% vs 10% to 30%, respectively (National Center for Health Statistics, 1986; Sternbach, 1987; Harkins *et al.*, 1994; Bressler *et al.*, 1999).

Because of the multidimensional nature of pain, it is difficult to place pain and its role in the current notions of QOL in LTC. Pain is generally acknowledged to be a complex, subjective phenomenon that encompasses nociceptive, perceptual, cognitive, and emotional factors (Melzack and Wall, 1965; Melzack and Casey, 1968; Loeser, 1980; Turk *et al.*, 1983). Pain has been found to be significantly correlated with cognitive impairment (Ferrell *et al.*, 1995), activities of daily living (Clifford *et al.*, 2003), depression (Clifford *et al.*, in press), and dysfunctional behaviors (Clifford *et al.*, 2003). Thus, pain is likely to play an important role in QOL in LTC.

The literature reviewed above supports the conceptualization that quality of life in LTC is a *process* composed of many variables interacting with one another. By definition, most people living in LTC are unable to live independently because of disabling conditions, such as a severe chronic illness, weakness, or dementia, which may influence other variables such as dysfunctional behaviors and depression, which may in turn exacerbate other variables such as level of assistance required or cooperation with ADLs. ADLs—the levels at which residents can

function independently—are often considered the ultimate manifestation of QOL. In the younger rehabilitation population, functional capacity is the most common indicator of treatment success (Turk, 1996). Path analytic studies by the authors indicated that psychological and emotional variables interacted with one another to ultimately predict functional capacity in a sample of persons suffering from chronic pain and associated medical conditions (Cipher *et al.*, 2002).

Although there have been a few correlational studies that have examined the interrelationships of QOL variables in LTC, a model that statistically examines the directional nature of these variables has not yet been developed and tested. We currently have evidence that cognitive impairment, depression, pain, activities of daily living, and behavioral disturbances are at least partially interrelated (Clifford *et al.*, 2003, Clifford *et al.*, in press). The purpose of the present study was to test two competing path models that are composed of QOL variables, including chronic illnesses, cognitive impairment, depression, pain, behavioral disturbances, and activities of daily living. We conceptualize ADLs to be an endpoint of this collection of LTC quality of life variables, in that chronic illnesses, cognitive impairment, depression, pain, and behavioral disturbances interact with one another to ultimately affect residents' functional capacity—the level at which residents can function independently.

## METHOD

### *Participants*

The study sample consisted of 234 residents living in a total of eight long-term care facilities in the Dallas, Texas area. Seven of the long-term care facilities were skilled nursing units, and one was a long-term acute care facility. Seventy-five percent of the sample consisted of females, and the average age was 82 years ( $SD = 9.3$ ). The sample was predominantly Caucasian (89%), followed by African-American (4%) and Asian American (2%). Seventy-two percent ( $n = 168$ ) of the sample reported persistent pain (pain experienced most of the day) and/or recurrent pain (pain experienced most days of the week). Of those residents, pain was reported to have been experienced an average of 71% of the time. Residents were suffering from more than two chronic medical conditions on average ( $\bar{X} = 2.7$ ,  $SD = 1.8$ ), the most common condition being hypertension (47%), followed by coronary artery disease (38%), cerebral vascular

damage (29%), diabetes (24%), congestive heart failure (24%), atrial fibrillation (20%), chronic obstructive pulmonary disease (17%), and kidney disease (8%).

### Measures

*Chronic Illnesses.* The number of illnesses that patients were experiencing, that are associated with their own ICD-10 code, were summed and used to represent the frequency of chronic illnesses.

*The Geriatric Multidimensional Pain and Illness Inventory (GMPI; Clifford et al., in press).* The GMPI is a 12-item instrument designed to assess pain and its functional, social, and emotional consequences. The first item is, 'How bad is your pain right now?' All items are rated on a ten-point scale, with each point associated with specific behavioral criteria. The scaling of the items is behaviorally-oriented because the GMPI is rated by a clinician who can only rate based on what the rater and the staff members can observe. The GMPI is composed of three subscales: Pain and Suffering, Interference, and Emotional Distress. The Pain and Suffering subscale was used for this study to represent pain levels. The GMPI has been evidenced to have excellent internal consistency ( $\alpha = 0.88$ ), and test-retest reliabilities for the three subscales have ranged from 0.62 to 0.96. Higher values are indicative of higher levels of pain.

*Geriatric Depression Scale (GDS; Yesavage et al., 1983).* The shortened (15-item) version of the GDS is a clinician-rated inventory that assesses depression. The GDS was standardized specifically toward the elderly population. An example of an item is 'Do you think it is wonderful to be alive?' Respondents answer each item with either 'yes' or 'no'. The 15-item version has good interrater reliability, with values ranging from 0.70 to 0.87 (Van Marwijk et al., 1995). Higher GDS values are indicative of higher depression.

*Neurobehavioral Cognitive Status Examination (NCSE; Kiernan et al., 1987).* The NCSE is a clinician-administered examination of impairment in orientation, repetition, naming, attention span, comprehension, short-term memory, constructional ability, social judgment, abstraction, and calculation. The NCSE uses a differentiated approach to assess various aspects of cognitive functioning, and was developed to overcome weaknesses of other brief instruments. Higher values are indicative of higher cognitive

functioning; lower values are indicative of impairment. The NCSE has good reliability and validity indicators, and has been evidenced to have a low false-negative rate (Schwamm et al., 1987). For this study, the ten NCSE scale scores were combined into one composite score using principal components analysis. Higher numbers represent higher levels of cognitive functioning.

*Psychosocial Resistance to Activities of Daily Living Index (PRADLI; Clifford et al., 2003).* The PRADLI is a eight-item clinically rated instrument that assesses the resident's level of functional independence and cooperation with eight psychosocially-related activities of daily living. The eight domains are: Up time, Eating Habits, Dressing, Toileting, Bathing, Medical Compliance, Restorative Care, and Social/Recreational Activities. These items are rated on a seven-pronged scale, with 1 representing the lowest levels of independence and cooperation, and 7 representing the highest levels of independence and cooperation. For this study, the eight items were combined into one composite score using principal components analysis. The PRADLI has been evidenced to have excellent internal consistency ( $\alpha = 0.88$ ) and high convergent validity (from 0.95 to 0.98). Higher numbers represent higher levels of independence.

*Dysfunctional behaviors.* Residents were rated on the average intensity of each of 26 possible behaviors, including agitation, verbal aggression, withdrawal, and physical aggression. Ratings were made on a seven-pronged scale, with lower numbers representing the least intensity (1 = 'Tolerable'), and progressive ratings of mildly distressing, moderately distressing, disruptive to self or others, interfering in medical care, possible danger to self of others, and (7 = 'Immediate Danger to Self or Others'). These ratings have been evidenced to have excellent internal consistency ( $\alpha = 0.96$ ). Test-retest coefficients have ranged between 0.86 to 0.94 among three raters.

### Procedure

The GMPI, GDS, NCSE, PRADLI, and behavior ratings were a part of neuropsychological evaluation that was administered by a licensed clinical geropsychologist. This sample consisted of patient referrals from attending physicians to a clinical geropsychologist for reasons related to change in cognitive functioning, emotional distress, or behavioral

dysfunction associated with dementia. The evaluation was verbally-administered, and feedback from the LTC staff was considered when rating, scoring, and interpreting each of these instruments.

### Data analysis

As mentioned above, two of the variables in the path model (cognitive impairment and ADLs) were represented by a composite of the instruments' items. In regression procedures (such as path analysis), statistical power is increased when potentially redundant items are combined (Stevens, 1992; Tabachnick and Fidell, 2001). Principal components analysis is a method whereby the variance shared between items is transformed into a number (factor score) representing the overlap between the items. In the case of the NCSE and PRADLI, principal components analysis of the items revealed a simple structure (the combined items represent only one concept). When simple structure is evidenced, principal components analysis is the preferred method to create a composite variable (Stevens, 1992).

Intercorrelations were obtained for the QOL variable set, consisting of chronic illness, cognitive impairment, pain levels, behavioral dysfunction, depression, and activities of daily living. Path analysis using AMOS 3.6 (Arbuckle, 1997) was then conducted in order to obtain direct and indirect effects between the variables, allowance for error terms (e.g. measurement error), and an indication of overall 'fit' of these models. Path analysis also allowed for multiple dependent variables in one path model (as compared to multiple regression analysis, which only allows one dependent variable at a time to be analyzed). Path coefficients are either Pearson correlation coefficients or beta weights, depending upon the number of variables predicting the endogenous (dependent) variable (Schumacker and Lomax, 1996). Model fit indices yielded the difference between the path coefficients and original (correlation) coefficients among the variables. It should be noted that path analysis does not indicate causal relationships; rather, the results provide evidence for directional influences just as multiple regression analysis would evidence (Tabachnick and Fidell, 2001).

The first path model, as illustrated in Figure 1, shows chronic illness and cognitive impairment as predictors, pain levels, behavioral dysfunction, and depression as mediators, and activities of daily living as the response variable. This mediational model was compared to a non-mediational model (Figure 2), with chronic illness, cognitive impairment, pain

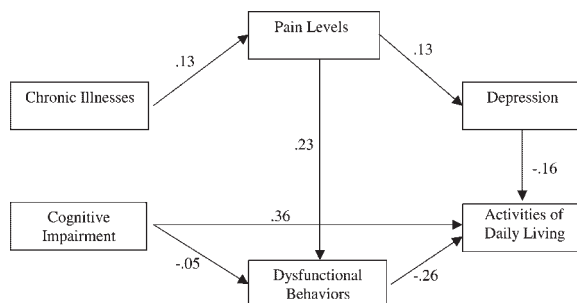


Figure 1. Mediation path model

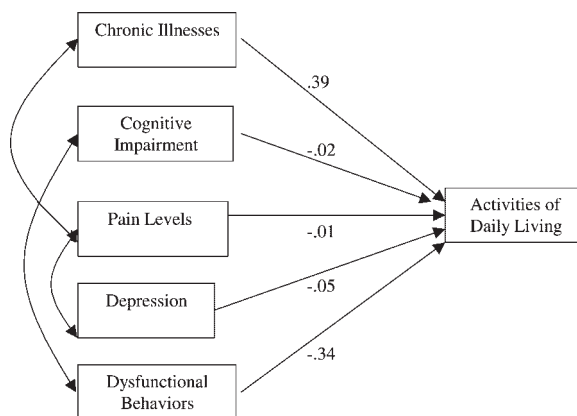


Figure 2. Non-mediational path model

levels, behavioral dysfunction, and depression as the predictors, and activities of daily living as the response variable. This nonmediational model was configured in a manner that is identical to a traditional multiple linear regression model. That is, this model consisted of a set of correlated predictors and one dependent variable.

The Binomial Index of Model Fit (Fraas and Newman, 1994) was computed for each model in order to determine the fit between the data and the proposed models. Low binomial indices of model fit indicate a good fit between the data and the model; high values indicate a poor fit (Fraas and Newman, 1994; Newman *et al.*, 1995). Finally, the mediational model was statistically compared to the nonmediational model with a chi-square test comparing numbers of significant paths in each model. This method is the recommended technique when comparing two non-nested models with equal degrees of freedom and/or the same number of paths (Newman, personal communication, March 2001).



RESULTS

All of the variables in the model were approximately normally distributed. Skewness and kurtosis indices did not exceed 1.0, and ranged mostly between 0.2 and 0.5. Descriptive statistics for the QOL variable set revealed that on average, residents were experiencing moderate levels of pain, almost three chronic illnesses, and moderate levels of depression (see Table 1). Correlational analyses revealed activities of daily living to be significantly correlated with cognitive impairment, depression, and dysfunctional behaviors, but *not* with pain levels or chronic illnesses. Pain levels were significantly correlated with chronic illnesses, depression, and dysfunctional behaviors (see Table 2).

The fit indices generated from the path analyses for the mediational and non-mediational models are shown in Table 3. The fit indices for the mediational model indicate a good model fit between the data and the model. The predictor variables in the path model accounted for 35% of the collective variance in activities of daily living. The chi-square was 7.2 ( $p=0.52$ ), meaning that the model accounted for the observed data without significant deviation, and that the observed (original,  $S$ ) and estimated (reproduced,  $\Sigma$ ) correlation matrix did not significantly differ. Other goodness of fit indices, such as the GFI, AGFI and RMSEA, also were indicative of a good model fit. The non-mediational model, on the other hand, yielded a chi-square of 18.6 ( $p=0.01$ ), with other indices of model fit also suggesting a poorer model fit (see Table 3).

All path coefficients in the mediational model except for one were significantly different from zero ( $p < 0.053$ ; see Table 4). The mediational model was found to have a substantially higher number of significant path coefficients (6 paths vs 2 paths;  $\chi^2 = 3.75$ ,  $p = 0.05$ ; see Table 4). Moreover, the Binomial Index of Model Fit (Fraas and Newman, 1994) for the mediational model was 0.063, while the Binomial Index for the nonmediational model was 0.656. Therefore, the data appear to provide substantial support for

Table 2. Correlations among QOL variables ( $n = 234$ )

	1	2	3	4	5	6
1. Pain levels**	1.00					
2. Chronic illnesses	0.13*	1.00				
3. Cognitive impairment	0.11	0.06	1.00			
4. Depression	0.13*	0.08	0.12	1.00		
5. Dysfunctional behaviors	0.22*	0.05	-0.02	.07	1.00	
6. ADLs	-0.04	-0.04	.35*	-0.13*	-0.28*	1.00

\*Indicates significance at  $\alpha = 0.05$ .

\*\*1. GMPI Pain and Suffering subscale; 2. NCSE composite score; 3. Depression: GDS score; 4. Average intensity of all dysfunctional behaviors; 5. PRADLI composite score.

the mediational model as opposed to the nonmediational model.

DISCUSSION

The purpose of this study was to develop and test a model that statistically examines directional relationships between chronic illnesses, cognitive impairment, depression, pain, behavioral disturbances, and activities of daily living. We tested two competing path models that composed these variables. Our measure of ADL was the ‘endpoint’ in both models, as much research on QOL defines functional capacity—the level at which residents can function independently—as the ultimate manifestation of QOL. This measure, however, also includes ‘time out of bed’ and ‘time spent participating in social and recreational activities.’ The traditional ADL domains and these additional measures of ADL are also important behavioral variables that can be enhanced by psychotropic and behavioral interventions. Our analyses revealed that the mediational model yielded the better model fit, as evidenced by various model fit indices and significant path coefficients, and thus suggests components of assessment and treatment outcome for psychiatric and psychological interventions.

These findings indicate that cognitive, emotional, and behavioral variables interact with one another to predict patients’ activities of daily living. Interestingly, pain levels did not influence activities of daily living directly, but rather influenced behavioral disturbances and depression, which in turn influenced activities of daily living. This pathway lends support to the assertions of Nagamoto *et al.* (1997) who postulated that cognitive impairment may affect functional capacity via behavioral disturbances. Likewise, pain levels

Table 1. Descriptive statistics for QOL variable set

	Mean	Standard Deviation
Pain levels	4.98	1.93
Chronic illnesses	2.68	1.65
Cognitive impairment	0.10	0.91
Depression	7.75	3.12
Dysfunctional behaviors	4.43	0.76
ADLs	0.09	0.99

Table 3. Model fit indices for mediational vs non-mediational path models

Criterion	Mediational model value	Non-mediational model value	Acceptable level
Chi-square ( $\chi^2$ )	7.2 (8), $p = 0.52$	18.60 (7) $p = 0.01$	Non-significant Chi-square value
GFI (Goodness of fit)	0.99	0.97	0 (no fit) to 1 (perfect fit)
AGFI (Adjusted GFI)	0.97	0.92	0 (no fit) to 1 (perfect fit)
RMSEA (Root-mean-square error of approximation)	0.000	0.09	< 0.05
Binomial Index of Model Fit	0.06	0.66	Lower values indicate better model fit

Table 4. Path coefficients in the mediational vs non-mediational model

Path	Mediational model	Non-mediational model
Chronic illnesses → Pain	$\beta = 0.13^*$	—
Pain → Depression	$\beta = 0.13^*$	—
Pain → Dysfunctional behaviors	$\beta = 0.23^*$	—
Cognitive impairment → Dysfunctional behaviors	$\beta = -0.05$	—
Dysfunctional behaviors → ADLs	$\beta = -0.26^*$	$\beta = -0.34^*$
Cognitive impairment → ADLs	$\beta = 0.36^*$	$\beta = 0.39^*$
Depression → ADLs	$\beta = -0.16^*$	$\beta = -0.05$
Chronic illnesses → ADLs	—	$\beta = -0.02$
Pain → ADLs	—	$\beta = -0.01$

\*Indicates significance at  $\alpha = 0.05$ .

were also found to affect functional capacity via behavioral disturbances. Thus, residents with severe cognitive impairment who have difficulty expressing their pain may manifest it through more salient outlets such as agitation, aggression, or withdrawal.

#### CLINICAL IMPLICATIONS FOR LTC CAREGIVERS

The mediational model has clinical implications for maximizing QOL in LTC settings where residents with cognitive impairment and chronic illness require varying levels of assistance in ADLs. Prior research with outpatients suffering from chronic pain and other chronic illnesses has indicated that patients have differing styles and inconsistencies in their report of chronic pain and other symptoms that limit their functional capacity (Cipher *et al.*, 2002). Thus, it follows that LTC residents with cognitive impairment are also likely to vary in their report of chronic pain and other symptoms that limit their participation in ADLs (Clifford *et al.*, in press). The resident's resistance to ADLs is often attributed to depression or dysfunctional behaviors associated with dementia. These conditions are often treated with psychopharmacological interventions and cognitive-behavioral therapy (Hay *et al.*, 1998; Lichtenberg *et al.*, 1998; Mintzer *et al.*, 1998; Coleman and Fox, 2002).

The mediational model also suggests that concurrent to the above assessment and treatment interventions, chronic or intermittent pain (and other noxious medical symptoms) need to be *routinely* treated or managed in order to reduce depression and dysfunctional behaviors that interfere with ADLs. Many residents who suffer from dementia and intermittent chronic pain do not ask for 'as needed' pain medications. Rather, they act out in agitated resistance to the ADL, decline to participate in the ADL, or request to stay in bed or to be put back into bed because of some unreported or reported noxious symptom. Routine analgesic and behavioral therapy can be individually applied in order to measurably improve the resident's QOL. Multidisciplinary evaluation should assess individual differences and coordinate interdisciplinary treatment in order to maximize QOL in LTC.

Clinicians who specialize in dementia, chronic illnesses, dysfunctional illness behaviors, chronic pain assessment (both verbal and nonverbal), psychiatric disorders, and the behavioral management associated with each of the above conditions, can use this mediational model as a treatment heuristic. Physicians, psychologists, rehab therapists, nurses and caregivers working in LTC can use the mediational model as an assessment tool for the effectiveness of interdisciplinary care in LTC, which maximizes QOL.

## CONCLUSIONS

Future research is encouraged to validate this QOL model in other residents of long-term care facilities. Our sample consisted largely of chronically-ill residents, most of whom were not ambulatory, had moderate levels of dementia, and who were referred to a psychologist for evaluation and treatment because psychiatric conditions and dysfunctional behaviors were interfering with ADLs and QOL. Thus, there are limitations in the extent to which we can generalize our findings to the general LTC population. Moreover, further comparative models are needed to test against this QOL model in order to find the best multidimensional treatment model for healthcare providers in long-term care. Nevertheless, we believe this study is an important first step in understanding how certain quality of life variables are related to one another.

These preliminary findings suggest that decreasing pain and other noxious symptoms (dizziness, shortness of breath, nausea, etc.) is likely to enhance overall improvements. Psychologists, who can recognize verbal and non-verbal illness behaviors that may be indicative of pain and/or depression, can play an important role in assisting physicians, nurses, and other LTC staff in the assessment and treatment of chronic and recurrent pain in LTC settings, and thus maximize QOL.

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