



HHS Public Access

Author manuscript

J Pain Symptom Manage. Author manuscript; available in PMC 2020 November 01.

Published in final edited form as:

J Pain Symptom Manage. 2019 November ; 58(5): 871–877. doi:10.1016/j.jpainsymman.2019.07.023.

Assessing the Reliability and Validity of a Brief Measure of Caregiver Quality of Life (CQLI-R)

Debra Parker Oliver, PhD, MSW [Professor],**

Department of Family and Community Medicine, University of Missouri, Medical Annex 306, Columbia, Mo 65212

George Demiris, PhD [Penn Innovates Knowledge Professor],

Department of Biobehavioral Health Sciences, School of Nursing, University of Pennsylvania, 418 Curie Blvd, Room 324, Philadelphia PA 19104

Robin L. Kruse, PhD [Professor],

Department of Family and Community Medicine, University of Missouri, Medical Annex 306, Columbia, Mo 65212

Jamie Smith [Analyst],

Department of Family and Community Medicine, University of Missouri, Medical Annex 306, Columbia, Mo 65212

Karla Washington, PhD, MSW [Assistant Professor]

Department of Family and Community Medicine, University of Missouri, Medical Annex 306, Columbia, Mo 65212

Keywords

Caregiver Quality of Life; Hospice; Measurement

Background

Cecily Saunders outlined a set of principles supporting modern hospice care. Among the unique aspects of hospice is the principle that both the patient and family should be seen as the unit of care.¹ For many years, research in hospice was focused on the patient. However, interventions targeting caregivers of hospice patients are becoming more common. Measurement instruments designed for the unique needs of the hospice setting are limited, and psychometric testing of these instruments is even more limited.² Quality of life for caregivers is an important concept, as caregiving has been found to have a negative impact on aspects of the physical health and mental health of caregivers, including exhaustion, sleep disturbance, and overall general health.^{3–5}

Quality of life is one outcome frequently measured in end-of-life research. The construct is challenging, and multiple attempts have been made to define, operationalize, and measure it. One of the challenges in measuring this concept has been confusion with its relationship to

**Corresponding Author: oliverdr@missouri.edu.

quality of care. For the components of quality of life to serve as indicators for quality of life, there is an assumption that improved quality of care can improve quality of life.⁶ It is therefore important that the indicators of quality of life and quality of care are specified.^{7,8}

Another deficit in constructs of quality of life has been the exploration of differences in the experiences of patients and their family members. While patients may have an excellent quality of life, their caregivers may be overwhelmed in helping to maintain that quality and as a result have a poor quality of life themselves. This is evidenced in the negative impacts research has identified in caregivers of the dying.³⁻⁵ Saunders principle of the patient and the family as the unit of care makes it imperative that end of life research focus on both the patient and the caregiver.

Conceptual Model of Patient and Family Quality of Life

Operationalizing quality of life domains for measurement has proven to be decidedly challenging, given their complexity. Foundational to the measurement and operationalization of any concept is a framework that links the measurement components and describes their relationship. A solid framework can also demonstrate what a concept is not. In this case, quality of life is an outcome of quality of care, it is not the same concept. Additionally, the components of quality of life for patients may be unique to the dying experience and the family components unique to the caregiving experience.

Anita Stewart and colleagues developed a conceptual model of quality of life for dying patients and their families. They note the importance of separating quality of life from the structure and process of a health care service and the perceived quality of care. Their complex model had three overarching domains: 1) patient and family factors; 2) structure and processes of care; and 3) patient and family outcomes, including satisfaction with care and quality and length of life.⁹ Within the domain of family outcomes, Stewart's team defines quality of life for family as comprising physical comfort, psychological well-being, social functioning, economic resources, and spiritual well-being.⁹

Stewart's team separates the components of quality of life by patient and their family member noting that although quality of life domains for family members are often the same as patients, there may be differences in how they are experienced.⁹ For example, while psychological well-being is an important quality of life domain for both patients and their family members, having a sense of not being a burden to others may be important for patients, whereas family members may worry the care they provide is inadequate to meet the patient's needs.

History of the CQLI and CQLI-R

To address the need for a tool to assess the quality of life of family members involved in caregiving activities, the CQLI (Caregiver Quality of Life Index) was first introduced in 1994.¹⁰ Based on a review of the literature at the time, the tool conceptualized quality of life as inclusive of four domains: emotional, social, physical and financial quality of life. The CQLI originally used one item to measure each of the four quality-of-life domains in the form of a visual analogue scale. Individuals placed a mark on a 100mm line to represent

their emotional, social, physical, and financial quality of life, with anchors at either end denoting the lowest and highest quality of life.¹⁰ The internal consistency of the original CQLI was determined to be quite good (Chronbach's alpha =0.88).¹⁰ Construct validity was evaluated by comparing the responses of 68 hospice caregivers against an equal number of non-caregivers. On a scale of 0–100, the mean score for caregivers (61.45, SD = 21.5) was significantly different from non-caregivers (76.19, SD = 16.3), suggesting there was a difference between the constructs for caregivers and non-caregivers.¹⁰ In a 1999 publication using the CQLI with 118 caregivers, the total mean score was 257.9 (SD = 84.1) out of a total of 400 (four subscales of 100). There were no significant differences in total score or item scores from admission to week four for 74 caregivers who remained in the study.¹¹ Despite its brevity, this instrument emerged as a short and simple, yet effective way to assess caregiver quality of life.¹¹

In 2005 Courtney and colleagues modified the CQLI, transforming its visual analogue scales into numerical rating scales (0 = lowest quality of life, 10 = highest quality of life) that could be administered verbally.¹² The anchors and descriptors remained the same as the original instrument, and the instrument was administered both in paper format and verbally to a convenience sample of 25 adults. Test-retest stability, internal consistency, and stability between versions were found to be comparable. Thus, the CQLI-R was determined to be an equivalent measure to the CQLI.¹²

Despite its limited history and prior testing in relatively small studies, our research team has successfully utilized the CQLI-R in several hospice and palliative care research projects, creating a unique opportunity to determine its psychometric properties when administered to a much larger pool of research participants. Thus, we undertook a study to evaluate the reliability and validity of the CQLI-R when used in hospice family caregiver research.

Methods

Data were drawn from three randomized controlled trials. The first was the ACTIVE trial, which tested an intervention in which family members used videoconferencing technology to participate in hospice interdisciplinary team meetings. The sample included family caregivers of hospice patients with any terminal diagnosis¹³. The second study from which data were drawn is the ACCESS trial (R01CA203999), which tests an intervention that builds on ACTIVE by adding online support and educational content. ACCESS includes only caregivers of hospice patients with cancer. Finally, data were also drawn from the PISCES trial, which tested a problem-solving intervention for family caregivers of hospice patients.¹⁴ As in ACTIVE, caregivers of hospice patients with any terminal diagnosis were included in the study sample.

In each of the three trials, the CQLI-R was administered at baseline and up to 22 days (range of 8–22 days) later to hospice family caregivers who had been randomized into an intervention or control group. Instrument reliability was determined using test-retest analysis between the baseline and second measure. Item analysis assessed the correlations between variables in both the subscales and the total instrument score.

Construct validity was assessed by comparing items to similar instruments within the same data set (see Table 1). The CQLI-R emotional domain was compared against psychosocial measures including the Patient Health Questionnaire-9 (PHQ-9)¹⁵ which measures depression, the General Anxiety Inventory (GAD-7)¹⁶ which is a common measure of anxiety, the Short Health Form (SF-12)^{17,18} which contains a mental health component, the Caregiver Reaction Assessment (CRA)¹⁹ emotional subscale, and the Zarit Burden Interview²⁰ subscale on emotional burden. The Physical domain of the CQLI-R was compared with the sleep item on the PHQ-9, the total SF-12 score, and the physical health subscale of the CRA. The social domain of the CQLI-R was correlated to the Lubben social network score (LSSN-6)²¹ which counts the number of individuals someone has in their social support system, and the social component of the SF-12. Finally, the financial domain used the variable income, the financial subscale of the CRA, and the financial components of the Zarit Burden Interview.

Results

The combined dataset represents 396 caregivers of hospice patients enrolled in three separate randomized controlled trials. Table 2 summarizes participants' demographic characteristics. The mean CQLI-R total scores for each study ranged from 24.5 to 29.3 out of a possible 40. There were no significant differences between the studies with regard to total or subscale scores.

Table 3 includes results of the test-retest analysis. Only two subscales (social and physical) in one study (ACTIVE) differed significantly between baseline and the second measure. Otherwise, baseline and second measures did not differ, indicating adequate test-retest reliability. Table 4 details the interclass correlations (ICC). The ICC between all subscales in all three trials varied from .52 to .79, indicating moderate to good ICC reliability.

Table 5 summarizes the construct validity assessment between the CQLI-R subscale and one or more comparison instruments in each trial. In every analysis, the CQLI-R subscale and the comparison outcome were significantly correlated ($p < .0001$) at baseline. The comparative outcomes analysis supports the construct validity of the CQLI-R.

Discussion

Measurement burden is a challenge in hospice research. Caregivers and patients are often under tremendous stress, and researchers must be sensitive to the burden created by any instrument. While the need for brief instruments for patients is based upon their physical ability to answer a battery of questions (cognition, fatigue, etc), the need for brief instruments for caregivers is based upon their burden. Caregiver burden has been documented as having a tremendous effect on caregiver health.²²⁻²⁴ Researchers need tools that do not add to this burden while trying to measure it. These data provide further support of the reliability of the brief CQLI-R and lend new evidence for construct validity.

The question of validity, however, is more complicated when assessing the CQLI-R. Although the correlations with similar instruments were strong, correlations are not a strong method to assess validity. When outlining their conceptual model, Stewart's team concluded

that additional research and conceptualization was needed to determine the validity of the domains they identified in quality of life. While suggesting their elements could be combined or possibly measured with one overall question, Stewarts team did not present data supporting any combination(s) but rather called for future research.⁹ Common measurement practice suggests a minimum of three questions to measure a construct and while the CQLI-R contains four total questions measuring quality of life, each of the four subscales includes only one question. In addition, it remains possible that consideration of more quality of life domains would enhance the validity of the CQLI-R. For example, addition of a subscale focused on spiritual quality of life, which has been identified as a key domain in prior work⁹, might strengthen the tool's ability to validly assess caregiver quality of life. Thus, the CQLI-R's content validity remains questionable.

Conclusion

Quality of life is an important outcome for measuring family members' experiences caring for a dying family member. Despite its brevity, this simple four-item CQLI-R appears to have respectable reliability across studies that assess hospice caregiver quality of life. However, its use as an exclusive measure is not advised given the limited evidence supporting its content validity. Additional conceptualization and operationalization of the domains would strengthen its properties. The addition of a fifth domain, spirituality, appears justified according to Stewards conceptual framework and the hospice principles identifying spirituality as a core component of end of life care.

Acknowledgement:

We would like to acknowledge the valuable guidance of David Albright, PhD with the data analysis for this paper.

Research reported in this publication was supported by the National Cancer Institute R01CA 203999 (PI Parker Oliver) and National Institute of Nursing Research R01NR012213 (PI Demiris) and R01NR011472 (PI Parker Oliver). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

1. Saunders C Hospice care. *Am J Med* 11 1978;65(5):726–728 [PubMed: 81612]
2. Dy SM, Wolff JL, Frick KD. Patient characteristics and end-of-life health care utilization among Medicare beneficiaries in 1989 and 1999. *Med Care* 10 2007;45(10):926–930 10.1097/MLR.0b013e31812714a5 [PubMed: 17890989]
3. Delaney LJ, Van Haren F, Lopez V. Sleeping on a problem: the impact of sleep disturbance on intensive care patients - a clinical review. *Annals of intensive care* 2015;5:3. [PubMed: 25852963]
4. Washington KT, Parker Oliver D, Smith JB, McCrae CS, Balchandani SM, Demiris G. Sleep Problems, Anxiety, and Global Self-Rated Health Among Hospice Family Caregivers. *Am J Hosp Palliat Care* 2 2018;35(2):244–249. [PubMed: 28393543]
5. Hudson PL, Thomas K, Trauer T, Remedios C, Clarke D. Psychological and social profile of family caregivers on commencement of palliative care. *J Pain Symptom Manage* 3 2011;41(3):522–534 10.1016/j.jpainsymman.2010.05.006 [PubMed: 21123026]
6. Cohen SR, Mount BM. Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *J Palliat Care*. Autumn 1992;8(3):40–45
7. Donabedian A Evaluating the quality of medical care. *Milbank Mem Fund Q* 7 1966;44(3):Suppl: 166–206

8. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *Jama* 1995;273(1):59–65 [PubMed: 7996652]
9. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage* 1999;17(2):93–108 [PubMed: 10069149]
10. McMillan SC, Mahon M. The impact of hospice services on the quality of life of primary caregivers. *Oncol Nurs Forum* 1994;21(7):1189–1195 [PubMed: 7971429]
11. Weitzner MA, McMillan SC, Jacobsen PB. Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *Journal of Pain and Symptom Management* 1999;17(6):418–428 Doi 10.1016/S0885-3924(99)00014-7 [PubMed: 10388247]
12. Courtney K, Demiris G, Oliver DP, Porock D. Conversion of the Caregiver Quality of Life Index to an interview instrument. *Eur J Cancer Care (Engl)* 2005;14(5):463–464 10.1111/j.1365-2354.2005.00612.x [PubMed: 16274469]
13. Oliver DP, Albright DL, Kruse RL, Wittenberg-Lyles E, Washington K, Demiris G. Caregiver evaluation of the ACTIVE intervention: “it was like we were sitting at the table with everyone”. *Am J Hosp Palliat Care* 2014;31(4):444–453. [PubMed: 23713130]
14. Demiris G, Oliver DP, Washington K, Pike K. A Problem-Solving Intervention for Hospice Family Caregivers: A Randomized Clinical Trial. *J Am Geriatr Soc* 2019 10.1111/jgs.15894
15. Kroenke K, Spitzer RL. The PHQ-9: A new depression diagnostic and severity measure. *Psychiat Ann* 2002;32(9):509–515
16. Spitzer RL, Kroenke K, Williams JB, Lowe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med* 2006;166(10):1092–1097 10.1001/archinte.166.10.1092 [PubMed: 16717171]
17. Hagell P, Westergren A. Measurement properties of the SF-12 health survey in Parkinson’s disease. *J Parkinsons Dis* 2011;1(2):185–196 10.3233/JPD-2011-11026 [PubMed: 23934920]
18. Jakobsson U, Westergren A, Lindskov S, Hagell P. Construct validity of the SF-12 in three different samples. *J Eval Clin Pract* 2012;18(3):560–566 10.1111/j.1365-2753.2010.01623.x [PubMed: 21210901]
19. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 1992;15(4):271–283 [PubMed: 1386680]
20. Bachner YG, O’Rourke N. Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging Ment Health* 2007;11(6):678–685 10.1080/13607860701529965 [PubMed: 18074255]
21. Lubben J, Blozik E, Gillmann G, et al. Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *Gerontologist* 2006;46(4):503–513 [PubMed: 16921004]
22. Chan EY, Lim ZX, Ding YY, Chan YH, Lim WS. Development of a Brief Caregiver-centric Screening Tool to Identify Risk of Depression among Caregivers of Hospitalized Older Adults. *J Nutr Health Aging* 2019;23(6):578–585. [PubMed: 31233081]
23. Duimering A, Turner J, Chu K, et al. Informal caregiver quality of life in a palliative oncology population. *Support Care Cancer* 2019 10.1007/s00520-019-04970-3
24. Petursdottir AB, Svavarsdottir EK. The effectiveness of a strengths-oriented therapeutic conversation intervention on perceived support, well-being and burden among family caregivers in palliative home-care. *J Adv Nurs* 2019 10.1111/jan.14089
25. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med* 2001;16(9):606–613. [PubMed: 11556941]
26. Ullrich A, Ascherfeld L, Marx G, Bokemeyer C, Bergelt C, Oechsle K. Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC Palliat Care* 2017;16(1):31. [PubMed: 28486962]
27. Lowe B, Decker O, Muller S, et al. Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Med Care* 2008;46(3):266–274 10.1097/MLR.0b013e318160d093 [PubMed: 18388841]

28. Grov EK, Fossa SD, Tonnessen A, Dahl AA. The caregiver reaction assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. *Psychooncology* 6 2006;15(6):517–527 10.1002/pon.987 [PubMed: 16189843]
29. Gandek B, Ware JE, Aaronson NK, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. *International Quality of Life Assessment. J Clin Epidemiol* 11 1998;51(11):1171–1178 [PubMed: 9817135]
30. Vilagut G, Forero CG, Pinto-Meza A, et al. The mental component of the short-form 12 health survey (SF-12) as a measure of depressive disorders in the general population: results with three alternative scoring methods. *Value Health* 6 2013;16(4):564–573 10.1016/j.jval.2013.01.006 [PubMed: 23796290]

Table 1:

Comparison Measures Between Scales to Establish Construct Validity

Measure	ACTIVE (n=263)	ACCESS (n=84)	PISCES (n=49)	CQLI-R Domain*
PHQ-9 Depression ²⁵	X	X		E ²⁶ , P
GAD-7 Anxiety ²⁷	X	X	X	E ²⁸
SF-12 ^{18,29,30}	X			T ^{5,26} , P, E, S
Lubben Social Network Score ²¹	X			S
Income	X	X		F ⁵
CRA ²⁸			X	T ⁵ , P ⁵ , E ⁵ , F ⁵
Zarit Burden ²⁰		X		T, E, F

PHQ = Patient Health Questionnaire; GAD = Generalized Anxiety Disorder; SF = Short Health Form; CRA = Cumulative Risk Assessment

CQLI-R Domains: E = Emotional, P = Physical, F = Financial, S = Social, T = Total

Table 2.

Baseline QOL total by caregiver demographics for each study

Characteristic	ACTIVE				ACCESS				PISCES			
	Frequency		QOL Total		Frequency		QOL Total		Frequency		QOL Total	
	N	%	M	SD	N	%	M	SD	N	%	M	SD
Overall	263	100.0	27.8	7.5	84	100.0	24.5	8.9	49	100.0	29.3	6.3
Gender												
Male	53	20.3	26.9	8.2	20	23.8	25.9	9.1	13	26.5	30.1	5.8
Female	210	79.8	28.0	7.3	64	76.2	24.0	8.8	36	73.5	29.1	6.8
Age												
Unknown	3	1.1							2	4.1		
20–50 years	57	21.7	25.8	8.6	24	28.6	23.0	8.2	4	8.2	23.5	2.4
51–65 years	120	45.6	27.8	7.2	42	50.0	23.9	8.7	20	40.8	29.7	6.7
66+ years	83	31.6	29.1	7.0	18	21.4	27.8	9.9	23	46.9	30.3	5.5
Education												
Unknown	2	0.7										
H.S./GED or less	79	30.0	26.4	8.53	23	27.4	26.6	8.3	3	6.1	28.3	3.1
Some college, trade school, other	91	34.6	27.7	7.7	30	35.7	23.9	9.4	9	18.4	25.0	7.2
Undergrad degree	56	21.3	28.6	6.6	19	22.6	21.4	7.5	24	49.0	31.1	5.0
Graduate degree	35	13.3	30.0	5.5	12	14.3	26.4	10.0	13	26.5	29.2	7.2
Income												
Unknown	28	10.6			8	9.5						
< 20k	58	22.0	23.7	7.4	12	14.3	18.4	10.3				
20–40k	85	32.3	27.1	7.9	16	19.0	22.0	6.5				
40–70k	43	16.3	30.2	6.4	16	19.0	26.2	8.4				
> 70k	49	18.6	30.9	5.7	32	38.1	26.8	8.8				
Lives with patient												
Unknown					3	3.6						
No	159	60.5	28.3	7.1	41	48.8	25.5	8.2	30	61.2	29.8	6.4
Yes	104	39.5	27.0	8.1	40	47.6	23.3	9.4	19	38.8	28.5	6.1

Table 3.

Descriptive statistics of CQLI-R subscales and total score, by study

Study	N	Emotional			Social			Financial			Physical			Total		
		M	SD	p	M	SD	p	M	SD	p	M	SD	p	M	SD	p
ACTIVE																
Baseline	263	7.2	2.1	.55	7.1	2.5	.009	6.4	2.8	.75	7.0	2.1	.05	27.8	7.5	.06
Time 2	263	7.2	2.1		6.8	2.6		6.5	2.7		6.8	2.2		27.2	7.6	
ACCESS																
Baseline	84	6.4	2.6	.13	5.8	2.9	.15	6.2	3.0	.66	5.9	2.2	.85	24.5	8.9	.26
Time 2	84	6.8	2.1		6.1	2.7		6.3	2.7		5.9	2.0		25.1	7.7	
PISCES																
Baseline	49	7.6	1.9	.91	7.5	2.4	.30	7.2	2.6	.32	7.0	1.8	.23	29.3	6.3	.15
Time 2	49	7.6	1.6		7.2	2.3		6.9	2.7		6.7	1.7		28.5	6.1	

p-value for paired t-test statistic.

Table 4:

Intra-Class Correlations, by domain and study

Domain	ACTIVE (n = 263)	ACCESS (n = 84)	PICSES (n = 49)
Emotional	.52	.61	.74
Social	.62	.67	.67
Physical	.69	.80	.62
Financial	.74	.64	.60
Total	.74	.79	.77

Shrout-Fleiss ICCs presented.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 5.

Baseline correlations between CQLI-R subscales and comparison scales, by study

Study and comparison scale	Baseline Quality of Life Subscale Score				
	Emotional	Social	Financial	Physical	Total
ACTIVE					
SF-12					
Body pain				0.52	0.45
General health	0.47			0.66	0.55
Mental health	0.59			0.62	0.62
Physical functioning				0.50	0.40
Role - emotional	0.51				0.58
Role - physical				0.60	0.54
Social functioning		0.36		0.56	0.54
Energy/fatigue	0.48			0.65	0.58
PHQ-9 Depression	-0.53				-0.59
PHQ-9 (sleep item)				-0.43	-0.42
GAD-7 Anxiety	-0.48				-0.59
Lubben Social Network Score		0.42			0.43
Income			0.47		0.35
PISCES					
GAD-7 Anxiety	-0.25				
Caregiver Reaction Assessment					
Health [†]				-0.53	
Self-esteem					
Financial [†]			-0.70		
Family support [†]		-0.60			-0.56
Total [†]					-0.74
ACCESS					
PHQ-9 Depression	-0.64				-0.69
PHQ-9 (sleep item)					-0.52
GAD-7 Anxiety	-0.57				-0.60
Zarit Burden	-0.49		-0.36		-0.46
Income			0.43		

All correlations $p < .0001$ [†]higher scores relate to doing worse health-wise or financially, having less support, and higher overall burden.