Serious Illness Strategy Session #3 – Measuring and Addressing Caregiver Strain and Well-Being

Serious Illness Strategy Sessions

National Quality Forum (NQF), with funding from the Gordon and Betty Moore Foundation, is leading a Serious Illness Initiative to advance serious illness-related quality measurement and engage and activate stakeholders around the importance of using quality measures to ensure the delivery of high-quality palliative care. As part of this initiative, NQF convened a Quality Measurement Committee to inform the work and hosted three strategy sessions aimed at developing and disseminating recommendations to advance quality measurement in serious illness care.

The first Strategy Session focused on bringing clarity and consistency to approaches used to identify individuals with serious illness. The second Strategy Session focused on assessing and addressing patient functional status in serious illness. The third Strategy Session, hosted in June of 2019, examined how to measure and address strain and well-being for caregivers of those with serious illness – a priority area identified by the Quality Measurement Committee. Key findings and recommendations are detailed below.

Serious Illness Initiative Strategy Session #3 Overview

Caregivers are critical partners in palliative care and are vulnerable to physical, social, and mental health issues, which in turn, affects care for those with serious illness. The Strategy Session on measuring and addressing caregiver strain and wellbeing had two objectives: (1) identify preferred caregiver assessment tools and discuss post-assessment steps, and (2) identify caregiver-related measure concepts and discuss measurement challenges and solutions.

Strategy Session Approach

NQF staff convened a multistakeholder technical expert panel (TEP) (Appendix A) including caregivers and caregiver advocates, clinicians, researchers, and program administrators with experience in palliative care, policy and payment, quality measurement, and caregiver strain and resilience. NQF staff also conducted an environmental scan to identify and review existing caregiver assessment tools, related quality measures, relevant guidelines, polices, standards, and practices.

Environmental Scan Results

Caregiver Assessment Tools

Caregivers of those living with serious illness experience a higher risk of burden, strain, and poor quality of life than those who are not engaged in a caregiving role. While there are a variety of federal and state policies and programs that address caregivers, the healthcare system inadequately addresses caregiver identification, assessment, and referral to supportive services. A systematic and well-designed assessment can help identify a caregiver's needs and strengths, and, in turn contribute to a plan of care that ensures the well-being of both care partners (the caregiver and seriously ill care recipient). The environmental scan identified systematic reviews of caregiver assessment tools that have been validated in a palliative care context, as well as several resource inventories of caregiver assessment instruments currently available for use by researchers, program developers, and clinicians. There are many instruments available, but no single tool, including multi-dimensional tools, captures all critical domains and subdomains for caregiver assessment. Additionally, there is a lack of clarity regarding when assessment tools should be used, who should conduct the assessment, and what action should take place following an assessment.

Caregiver-Related Quality Measures

NQF identified process and outcome measures that reference caregivers, with several specific to hospice and end-of-life care, and two related to home and community-based services. However, almost all the quality measures assess the care of the individual with serious illness and not the caregiver's well-being or strain. Existing measures use the caregiver as proxy respondent to evaluate experience of care, assess whether the caregiver received education, and whether plans were documented and shared with the caregiver. The scan also identified proposed measure concepts from A Convening on Quality Measures for Serious Illness Care, a conference held in 2017 in Banff, Canada. See Appendix B for full list of identified assessment tools and quality measures.

Key Takeaways from Expert Discussion

Caregiver Assessment Tools

The TEP reviewed seven conceptual domains that have been used in previous efforts to categorize caregiver assessment tools. These conceptual domains were established during a Family Caregiver Alliance-coordinated National Consensus Development Conference (NCDC), which convened 54 experts in caregiving, health and long-term care, and public policy. The seven conceptual domains are: (1) context of caregiver; (2) caregiver's perceptions of health and functional status of care recipient; (3) caregiver values and preferences; (4) well-being of the caregiver; (5) consequences of caregiving; (6) skills/abilities/knowledge to provide care recipient with needed care; and (7) potential resources that caregiver could choose. NQF cross-walked the sub-domains within the *well-being of caregivers* and *consequences of caregiving* conceptual domains with 11 caregiver assessment tools that have been validated in serious illness or palliative care contexts (Table 1).

Table 1. NQF Cross-Walk of NCDC Subdomains and Caregiver Assessment Tools

Assessment Tool	**BASC***	**CBS-EOLC**	**CIS**	**CRA**	**ZBI - 6-item**	**MCSI**	**FACQ-PC**	**CQOLC**	**QOLLTI-F**	**SF-36**	**CQLI-R**
Consequences of Caregiving Subdomains											
Physical health strain		✓		✓		✓	✓		✓	✓	✓
Emotional health strain	✓	✓					✓	✓	✓	✓	✓
Family Relationship Strain	✓		✓	✓	✓	✓	✓	✓	✓	✓	
Social Isolation			✓	✓			✓			✓	✓
Grief/Loss											
Work Strain			✓	✓		✓	✓			✓	
Financial Strain			✓	✓		✓	✓	✓			✓
Lifestyle /Scheduling	✓		✓	✓	✓	✓	✓	✓	✓	✓	

Assessment Tool	BASC*	CBS-EOLC	CIS	CRA	ZBI - 6-item	MCSI	FACQ-PC	CQOLC	QOLLTI-F	SF-36	CQLI-R
Caregiver Satisfaction w/ Helping Care Recipient	✓			✓			✓	✓	✓		
Well-being Subdomains											
Developing New Skills and Competencies			✓				✓				
Depression/Emotional Distress	✓	✓				✓	✓	✓	✓	✓	
Life Satisfaction / QoL	✓	✓			✓		✓	✓	✓	✓	
Self-Rated Health			✓	✓	✓		✓			✓	
Health Conditions	✓										

*BASC: Brief Assessment Scale for Caregivers; CBS-EOLC: Caregiver's Burden Scale in End-of-Life Care; CIS: Caregiving Impact Scale; CRA: Caregiver Reaction Assessment; ZBI 6-item: Zarit Burden Inventory, 6-item; MCSI: Modified Caregiver Strain Index; FACQ-PC: Family Appraisal of Caregiving Questionnaire for Palliative Care; CQOLC: Cancer, Quality of Life Index-Cancer; QOLLTI-F: Quality of Life in Life-Threatening Illness—Family Carer Version; SF-36; Medical Outcomes Study 36-item Short Form; CQLI-R: Caregiver Quality of Life Index-Revised

The TEP reviewed the validated caregiver assessment tools and sub-domains addressed by these tools and noted limitations in what the instruments address. No single tool, including multi-dimensional tools, could capture all important aspects of caregiver strain and well-being. The Panel emphasized that context of the caregiver (i.e., whether there are multiple caregivers, availability and capacity to support the person with serious illness, and caregiver access to financial and supportive resources) is a critical consideration. The possibility of there being multiple caregivers playing different roles, or that the person accompanying a patient at any given healthcare visit may not be the "primary" caregiver, pose significant challenges to caregiver identification—the first step in assessing caregiver strain and well-being.

Caregiver Identification and Education

There are currently no systems in place to identify caregivers, document this information, and share it across care settings, however, efforts are underway to address this first step in caregiver assessment. Notably, new state law known as the Caregiver Advise, Record, Enable (CARE) Act, requires that hospitals record the name of the family caregiver in medical records, inform the caregiver when the patient is discharged, and provide education and instruction of the medical tasks he or she will need to perform for the patient at home. Many of these tasks can be complex, such as managing multiple medications, providing wound care, managing special diets, giving injections, or operating monitors or other specialized medical equipment. Lack of confidence in preparedness to perform these types of tasks may be a significant source of anxiety and can contribute to a perceived inability to contend with role demands. The Panel noted that rather than measure satisfaction or the extent to which a caregiver develops new skills and competencies, it is more important to assess their confidence in ability to perform tasks. Education and resources should be provided when there is a gap between expected tasks that would need to be performed and caregiver confidence in performing those tasks.

Caregiver Strain and Resilience

The Panel discussed the concept of strain and wanting to ensure that this encompasses the physical strain of providing care, emotional strain – and how this can often result from frustrating interactions with the healthcare system, or from perceptions of feeling judged about the care they are providing or not providing – and financial strain, in terms of the ability to pay for healthcare or support services, access to health insurance, and the ability to take sick leave or time off work to care for their loved one. Financial strain is often referred to as the hidden cost of care, but the Panel urged moving away from this terminology because it's known to be a cost of care and should be something the system tackles rather than ignores.

The Panel also discussed the concept of wellbeing and felt that it did not adequately capture what might be most important for caregivers. Rather, they thought resilience might be a better overarching concept here. For the Panel, resilience included wellbeing, but also the concepts of caregiver confidence in performing caregiving tasks, which are often tasks that in a healthcare setting, would be performed by a skilled or licensed clinician. Resilience includes caregiver ability to cope and their sense of worry about their loved one and their own health and wellbeing, and the anticipated or actual grief and loss that comes with caring for someone with serious illness. This concept of anticipatory grief was raised to emphasize the point that for many caregivers there is a sense of impending loss that begins long before bereavement. The impending loss references not just the death of the person receiving care, but lifestyle changes that make it difficult to participate in certain activities and the potential loss of opportunities to pursue lifelong goals.

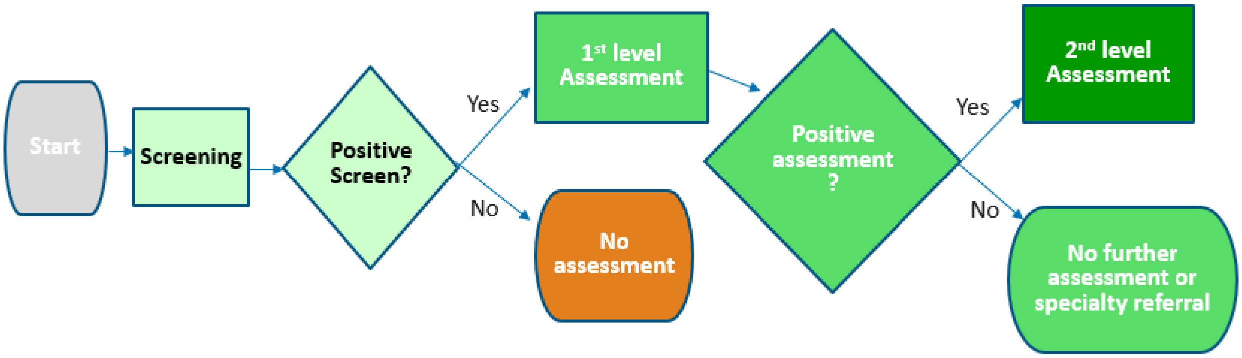
Given all these concepts, the TEP emphasized that no single tool captures the critical domains and subdomains. The panel shared that the tool created and used to assess caregivers needs to be clinically feasible, used widely and broadly disseminated, and applicable regardless of the setting of care. With the current limitations to identifying and assessment caregivers, the Panel proposed a step-wise approach that could be feasibly implemented to identify, assess, and address caregiver resilience. The proposed screen and assessment approach described by the Panel mirrors the model developed in a previous Strategy Session for implementing functional assessments into care (Figure 1).

Proposed Caregiver Identification and Assessment Approach

The caregiver assessment approach should begin with identifying who the caregiver or caregivers are, and what caregiving role(s) they play. The Panel noted that a significant challenge is that there may be multiple caregivers playing multiple roles. Some of these roles might include acting as an emergency contact, providing support for daily activities of living, or acting as a surrogate decision-maker or advocate for the person with serious illness. Frequency of caregiving was discussed as another potential area of ambiguity: Does the caregiver provide daily direct care at home or do they check in from time to time? Understanding the context in which the caregiver is providing care and the roles and responsibilities they are taking on are important considerations that can help inform next steps in assessment.

Following caregiver and role identification, the Panel suggested a stepwise approach beginning with a triage or screening aimed at identifying individuals who may need a more comprehensive assessment. For the screening phase, the Panel agreed it was important to identify brief or short-form tools to use, acknowledging that at any given healthcare visit, there is limited clinician capacity to address caregivers. A positive screen for significant strain or unmet needs would trigger the need for more in-depth assessment either by the same clinician at an appointed time or appropriate referral to another clinician or resource. A second-level or more in-depth assessment should ideally identify caregiver needs and inform appropriate linkages with home and community-based services, community-based organizations, or to additional training or educational resources. These referrals should fill in gaps for needed services.

Figure 1. Proposed Screening and Assessment Approach



The Panel discussed frequency and intensity of assessments, noting that burden is a serious concern. Tools that are currently in use should be prioritized as they have demonstrated ability for successful incorporation into clinical workflows. The Panel also discussed the possibility of using electronic assessment instruments that could be completed by the caregiver offsite at their own convenience. This would alleviate burden and time constraints in the clinical setting and perhaps improve accessibility by enabling engagement with caregivers that may not be present at healthcare visits with the seriously ill individual. The Panel acknowledged the downside that already burdened caregivers may be unlikely to complete a voluntary assessment electronically.

The Panel also emphasized the need for shared decision-making approaches to ensure that the person with serious illness' values, preferences, and goals are identified, and there is an opportunity to identify any disagreement or areas of discordance between what the person with serious illness wants and what the caregiver and/or care team is trying to achieve or recommend as part of the care plan.

Caregiver-Related Measure Concepts

Following discussions related to caregiver assessment tools and proposed approaches, the Panel turned to how caregiver-related quality measurement could be used to improve the quality of care for the person with serious illness and their caregiver(s). The Panel emphasized that quality measures should support caregivers and those with serious illness to receive the care and help they need. Structures and processes need to be in place to support caregivers and allow clinicians and those in the healthcare system to refer caregivers to resources in their communities. The Panel noted that any quality measure development should address caregivers in adult and pediatric populations, apply broadly across settings, including in the home, and acknowledge the various terms used in the real-world to describe caregivers (e.g., someone at home or lives close by who helps you).

The Panel identified three measure concepts to support identifying, assessing, and addressing caregiver needs and resilience. The first was a measure concept focused on caregiver identification. Identification is a critical first step that must happen before any assessment or provision of support is possible. The Panel noted that often those who are identified as caregivers by the care team or by the person with serious illness do not self-identify as a caregiver. Concordance between who is identified as the caregiver and who self-identifies as a caregiver is critical to ensuring the care team is communicating with the correct person and addressing their caregiving needs. Lastly, the TEP noted that while this measure concept should address whether a caregiver has been identified and documented in the care plan or electronic health record (EHR), it is important to connect those who do not have a caregiver with support services that may be able to fill this caregiving role.

The second measure concept identified was focused on identifying and meeting caregiver needs. Specifically, are caregivers being assessed, are their needs and goals being identified, are they referred to services and supports to meet their needs, and finally, are their needs and goals being met. This measure concept might be a composite measure that encompasses the step-wise assessment approach the Panel proposed to identify, assess, and address caregiver needs and resilience. The Panel noted, however, the need to provide programs with flexibility to account for the unique needs of the populations they serve, the resources available in their community, and the setting of care and context of the caregiver.

The final measure concept addresses caregiver strain and resilience and was focused on a single caregiver self-reported measure of distress maintained below a given threshold; this could be a quick indicator that caregiver needs were adequately addressed. This measure approach allows flexibility for community-based programs to implement structures and processes tailored to their populations and resources in order to achieve the caregiver-reported outcome of interest. The Panel discussed the power of acknowledging caregivers as people and asking how they are doing in the context of caring for their loved one. Many of the caregivers on the Panel shared that it is rare that a clinician asks about how they are coping, what they are worried about, or when their last “good day” was. They felt even these simple questions, regardless of whether the clinician was able to connect them to a service, recognized them as critical partners in the care of the person with serious illness.

Caregiver Resilience Measure Concepts
Caregiver Identification and Concordance: • Percent of persons with serious illness with caregivers identified in the care plan / record and the percent of those identified who self-identify as the caregiver(s) o Of those with no identified caregiver, percent linked to support services
Caregiver Needs Identified and Met: • Percent of caregivers with a complete assessment with: 1) needs and goals identified; 2) referral to appropriate services; 3) needs and goals met
Caregiver-Reported Resilience: • Percent of caregivers reporting that: o They are asked about their worries or their last “good day” o Their distress level is maintained below threshold

Advancing Quality Measurement for Caregivers of Those with Serious Illness

The Panel discussed several challenges and opportunities to advance quality measurement for caregivers of those with serious illness, including: 1) health information technology; 2) payment and reimbursement; and 3) the shift to person- and family-centered care.

Health Information Technology

Sharing information across settings and sectors may support caregiver identification and assessment as caregivers may be assessed in one setting (i.e., the home) and then asked similar questions when they accompany the person with serious illness to a clinical appointment. Including results from caregiver assessments in digital health tools such as patient portals and creating dedicated fields within a patient’s electronic health record to collect and store data related to caregiver needs would facilitate measurement and action on the results of assessments. Building this into electronic processes could also support linkages to resources within the healthcare system and support warm hand-offs to community-based resources. To facilitate the latter, the Panel recommended educational campaigns within healthcare settings to raise awareness of resources available in the community, such as peer support networks, to support caregivers of those with serious illness.

Payment and Reimbursement

First, payment and reimbursement can support caregiver assessment and data collection for quality measurement. Many clinicians, including primary care providers, have limited time with patients with serious illness and even less time with caregivers. Reimbursing clinicians and/or incentivizing caregiver assessments and linking caregivers to community-based resources would help advance quality in this area. Incentives based on the screening and referral measures would support broad dissemination and use of caregiver assessment tools. New payment models and/or demonstration projects could be used to test reimbursement for assessments and links to community-based resources and could help develop the business case for implementing caregiver assessments as part of high-quality serious illness care.

The Shift to Person- and Family-Centered Care

The shift to person- and family-centered care is another facilitator of assessments and quality measurement for caregivers of those with serious illness. The Panel highlighted the need to clarify the unit of measurement for the recommended quality measures: whether this was the patient, the caregiver, and/or the patient-caregiver dyad. Additionally, the Panel discussed whether the goal of measurement was to improve the care and outcomes of the person with serious illness or to improve the care and outcomes of the caregiver. The TEP acknowledged the importance of actionability of the assessment and measurement results; measurement for the purposes of improving the care of the person with serious illness may be a more actionable goal. As the field and quality measurement enterprise embraces person- and family-centered care, however, measures that address the family unit could play a greater role in assessing the quality of serious illness care.

Next Steps

The Strategy Session focused on caregiver strain and wellbeing illuminated many opportunities to advance quality measurement for caregivers of those with serious illness. Along with the results from the first two Strategy Sessions, this third Strategy Session lays out recommended measure concepts and considerations for measure development in serious illness care. Much work remains. NQF will consolidate all the expert insights and recommendations from across the Serious Illness Initiative to chart a path forward to advance the quality of care for those with serious illness in community-based settings.

APPENDIX A: Technical Expert Panel

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Appendix B: Environmental Scan Results

Caregiver Assessment Tools Validated in Serious Illness

Burden

Author, Year	Instrument Name	Population(s) Tested	Reliability	No. of items	Validity	Administration	Notes
Glajchen, 2005	**Brief Assessment Scale for Caregivers (BASC)**	Family caregivers of the medically ill	α=0.58-0.80	14	Construct	Self-completion or interviewer administered	4-point Likert scale from not at all to a lot. Assesses positive and negative personal impact, relationship with other family members, medical issues, concern about loved ones
Dumont, 2008	**Caregiver's Burden Scale in end-of-life care (CBS-EOLC)**	Family caregivers of terminal cancer patients	α=0.95	16	Construct-Convergent	Self-completion or interviewer administered	4-point Likert scale, never to very often – e.g., do you ever feel emotionally exhausted, physically exhausted, end of your rope, no longer capable of caring …
Cameron, 2002	**Caregiver Impact Scale (CIS)**	Caregivers of advanced cancer patients	α=0.87	14	N/A	Self-completion or interviewer administered	7-point Likert. Assesses extend providing care interfered with participation in 14 domains of lifestyle (health, employment, recreation)
Hudson, 2006; Given 1992, Grov 2005	**Caregiver Reaction Assessment (CRA)**	Caregivers of patients receiving palliative care for physical impairments, AD, and cancer. Also, spouses of colorectal cancer patients (nonpalliative stage).	α=0.76-0.83	24	Construct-Convergent	Unclear	5-point agreement Likert. Impact on schedule, caregiver esteem, family support, health, finances. Positive and negative aspects.

Higginson, 2010	**Zarit Burden Inventory (ZBI)**	Caregivers of patients with advanced conditions (adv cancer, dementia, acquired brain injury). Caregivers of patients with Heart Failure	α=0.69-0.93	22 (short form versions avbl.)	Construct-Convergent	Interviewer administered	Most widely used for measuring burden in clinical and research settings. 5-point Likert scales from never to nearly always. 12-, 7-, 6-, 4-, and 1-item short forms available. Research shows 12-item is suitable in all situations, and 6-item is suitable for brief screening in palliative care situations. 1-item suitable for rapid screening.

Burden – Tool Description

Tool	Description
Brief Assessment Scale for Caregivers (BASC)	Assesses positive and negative personal impact of caregiving, relationship with other family members, medical issues, concern about loved ones. 14 items. Self-report [1]
Caregiver's Burden Scale in end-of-life care (CBS-EOLC)	Assesses intensity of emotional, physical burden; psychological distress; discomfort with type of care being provided. 16 items. Self-report. [2]
Caregiver Impact Scale (CIS)	Assesses the extend providing care interfered with participation in 14 lifestyle domains (e.g., health, diet, employment, household responsibilities, active recreation). Self-report. [3]
Caregiver Reaction Assessment (CRA)	Assesses impact on schedule, caregiver esteem, family support, health, and finances. Positive and negative aspects. 24 items. Self-report [4]
Zarit Burden Inventory (ZBI)	Most widely used. Original ZBI is 22 item, but 6-item SF has comparable diagnostic utility. 6-item form assesses burden on time, conflicting responsibilities, relationship with others, strain, health, and agency. Interviewer administered [5]

Strain

Author, Year	Instrument Name	Population(s) Tested	Reliability	No. of items	Validity	Administration	Notes
Hwang, 2003	**Modified Caregiver Strain Index (CSI)**	Caregivers for symptomatic advanced cancer patients	α=0.84	13	Construct-Convergent	Self-completion or interviewer administered	At least one item for: financial, physical, psychological, social, and personal domains. 0-2 scale from (2) yes on a regular basis to (1) sometimes to (0) no. Higher scores indicate greater need for in-depth assessment to facilitate appr. intervention.
Cooper, 2006	**Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)**	Caregivers of palliative care patients	α=0.73-0.86	25	Face	Self-completion	4 subscales: strain, positive appraisals, distress, well-being.

Strain – Tool Description

Tool	Description
Modified Caregiver Strain Index (CSI)	Contains 13 questions that measure strain, with at least one item for financial, physical, psychological, social, and personal domains. Scoring ranges from 26 to 0; a higher score indicates a higher level of strain. Self report.[6]
Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)	Appraisal in four domains: caregiver strain (burden—role overload and captivity), positive aspects (e.g., commitment, confidence, intimacy, and satisfaction), distress, and family well-being. 25 items. Self report. Researchers note CIS can be used as assessment instrument or potential outcome measure for evaluating a palliative care intervention. [7]

Quality of Life

Author, Year	Instrument Name	Population(s) Tested	Reliability	No. of items	Validity	Administration	Notes
Weitzner, 1999, Mahendran 2014	**Caregiver Quality of Life Index – Cancer (CQOLC)**	Caregivers of cancer patients	α=0.91	35	Construct-Convergent	Self-completion (20 mins)	Widely used. 5-point Likert from not at all to very much. Assesses burden, disruptiveness, social support, positive adaptation, and financial concerns.
Cohen, 2006	**Quality of Life in Life-Threatening Illness-Family Carer Version (QOLLTI-F)**	Caregivers of palliative cancer patients.	α=0.86	16	Construct-Convergent	Self-completion. ~12 mins	0-10 scale from never to always. Assesses state of carer, patient wellbeing, quality of care, outlook, environment, finances, and relationships. Tested in treatment setting and home hospice. Based on qualitative interviews with carers reporting what is important for their QoL.
Ware 1992	**Medical Outcomes Study 36-item Short Form (SF-36)**	General population plus specific disease groups	N/A	36	N/A	Self-completion.	Concepts: physical fx, role limitations due to physical problems, social fx, bodily pain, mental health, role limitations due to emotional problems, vitality, general health perceptions. Diff response options for diff questions.
Ferrell 1995	**Quality of Life Family Caregiver Tool**	Family caregivers of cancer patients	N/A	27	N/A	N/A	N/A
McMillan 1994	**Caregiver Quality of Life Index-Revised (CQLI-R)**	Caregivers of cancer patients receiving hospice care	α=0.77	4	Face	Oral interview	4 single item subscales measuring emotional, social, financial, and physical QoL.

Quality of Life – Tool Description

Tool	Description
Caregiver Quality of Life Index – Cancer (CQOLC)	Assesses caregiving burden, disruptiveness, positive adaptation, and financial concerns. Widely used. 35 items. Self report. Approx. 20 minutes to complete. [8]
Quality of Life in Life-Threatening Illness-Family Carer Version (QOLLTI-F)	Assesses QoL in 7 subscales: carer's own state, environment, carer's outlook, quality of care, relationships, patient condition, and financial worries. 16 items. Self report. Approx. 12 minutes to complete. Built from qualitative interviews with caregivers probing important contributors to their QoL.[9]
Medical Outcomes Study 36-item Short Form (SF-36)	Widely used, generic QoL measure—but tested among specific disease groups. Assesses physical fx, physical role, emotional role, pain, social fx, mental health, energy/fatigue, general health perceptions, and change in health. 36 items. Self-admin or interviewer administered. [10]
Caregiver Quality of Life Index-Revised (CQLI-R)	Contains 4 single-item subscales that measure emotional, social, financial, and physical QoL on a scale of 0-10. Designed specifically for hospice caregivers. [11]

Caregiver Assessment Tools References

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Zarit Burden Inventory

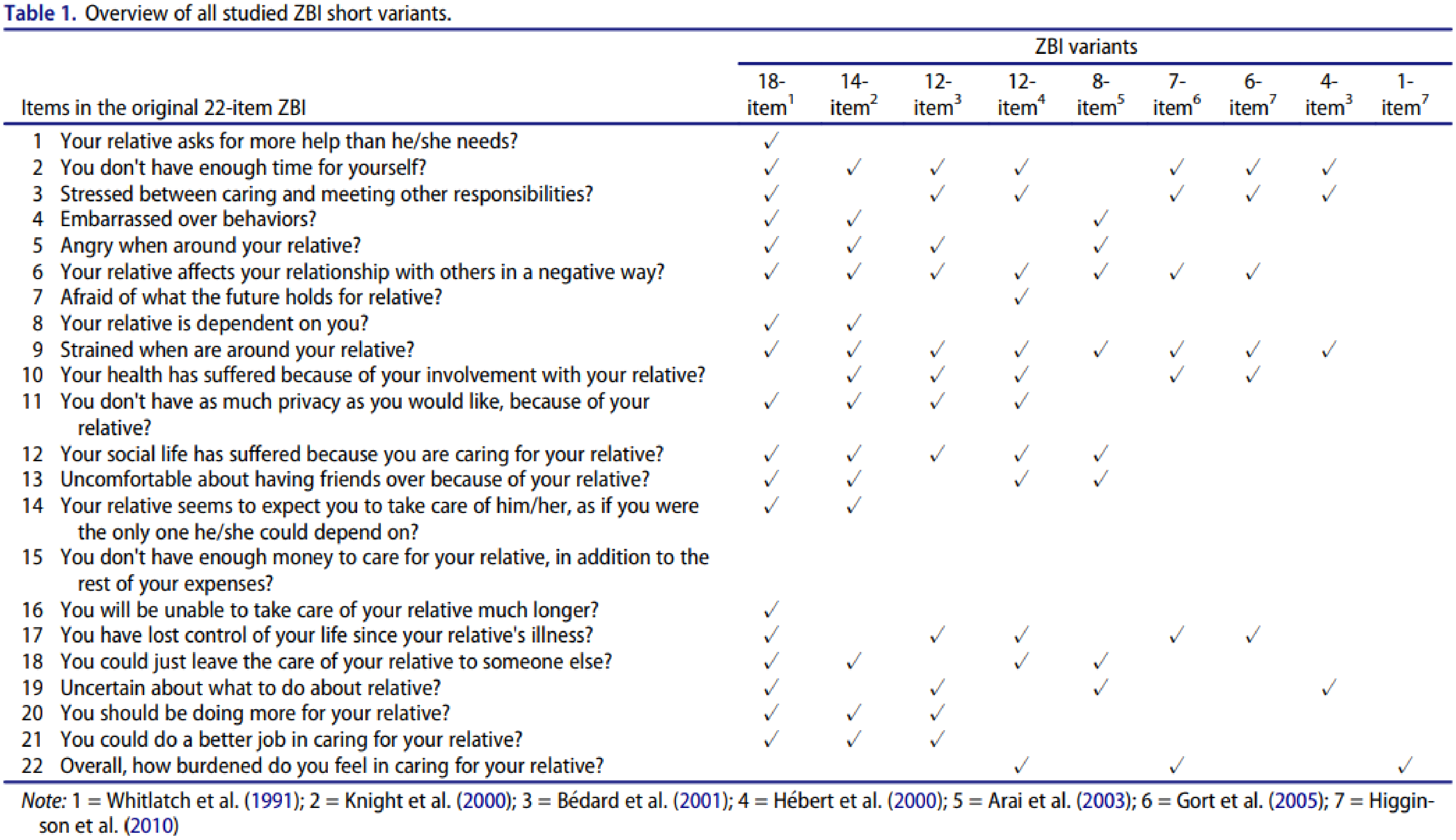

Table 1. Overview of all studied ZBI short variants.

	Items in the original 22-item ZBI	ZBI variants								
		18-item[1]	14-item[2]	12-item[3]	12-item[4]	8-item[5]	7-item[6]	6-item[7]	4-item[3]	1-item[7]
1	Your relative asks for more help than he/she needs?	✓								
2	You don't have enough time for yourself?	✓	✓	✓	✓		✓	✓	✓	
3	Stressed between caring and meeting other responsibilities?	✓		✓	✓		✓	✓	✓	
4	Embarrassed over behaviors?	✓	✓			✓				
5	Angry when around your relative?	✓	✓	✓		✓				
6	Your relative affects your relationship with others in a negative way?	✓	✓	✓	✓	✓	✓	✓		
7	Afraid of what the future holds for relative?				✓					
8	Your relative is dependent on you?	✓	✓							
9	Strained when are around your relative?	✓	✓	✓	✓	✓	✓	✓	✓	
10	Your health has suffered because of your involvement with your relative?		✓	✓	✓		✓	✓		
11	You don't have as much privacy as you would like, because of your relative?	✓	✓	✓	✓					
12	Your social life has suffered because you are caring for your relative?	✓	✓	✓	✓	✓				
13	Uncomfortable about having friends over because of your relative?	✓	✓		✓	✓				
14	Your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	✓	✓							
15	You don't have enough money to care for your relative, in addition to the rest of your expenses?									
16	You will be unable to take care of your relative much longer?	✓								
17	You have lost control of your life since your relative's illness?	✓		✓	✓		✓	✓		
18	You could just leave the care of your relative to someone else?	✓	✓		✓	✓				
19	Uncertain about what to do about relative?	✓		✓		✓			✓	
20	You should be doing more for your relative?	✓	✓	✓						
21	You could do a better job in caring for your relative?	✓	✓	✓						
22	Overall, how burdened do you feel in caring for your relative?				✓		✓			✓

Note: 1 = Whitlatch et al. (1991); 2 = Knight et al. (2000); 3 = Bédard et al. (2001); 4 = Hébert et al. (2000); 5 = Arai et al. (2003); 6 = Gort et al. (2005); 7 = Higginson et al. (2010)

Quality Measures

Experience-Related Quality Measures

#	Measure Title	Measure Description	Steward/Developer
2967	**CAHPS® Home- and Community-Based Services Measures**	Seven scale measures, 6 global rating and recommendation measures, and 6 individual measures derived from a cross disability survey to elicit feedback from adult Medicaid beneficiaries receiving home and community based services (HCBS) about the quality of the long-term services and supports they receive.	Centers for Medicare and Medicaid Services (CMS)
2651	**CAHPS® Hospice Survey (experience with care)**	Derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire intended to measure the experiences of hospice patients and their primary caregivers.	CMS
1632	**CARE - Consumer Assessments and Reports of End of Life**	Measures perceptions of the quality of care either in terms of unmet needs, family reports of concerns with the quality of care, and overall rating of the quality of care. The time frame is the last 2 days of life up to last week of life spent in a hospice, home health agency, hospital, or nursing home.	Center for Gerontology and Health Care Research
0208	**Family Evaluation of Hospice Care**	Derived from responses to 17 items on the Family Evaluation of Hospice Care(FEHC) survey presented as a single score ranging from 0 to 100 and is an indication of the hospice´s overall performance on key aspects of care delivery.	National Hospice and Palliative Care Organization

Education-Related Quality Measures

NQF #	Measure Title	Measure Description	Steward/Developer
0519	**Diabetic Foot Care and Patient Education Implemented**	% of home health episodes of care in which diabetic foot care and patient/caregiver education were included in the physician-ordered plan of care and implemented for diabetic patients since the previous OASIS assessment.	CMS
0520	**Drug Education on All Medications Provided to Patient/Caregiver During Short Term Episodes of Care**	% of short term home health episodes of care during which patient/caregiver was instructed on how to monitor the effectiveness of drug therapy, how to recognize potential adverse effects, and how and when to report problems.	CMS
0136	**Heart Failure (HF): Detailed discharge instructions**	% of HF patients discharged home with written instructions or educational material given to patient or caregiver at discharge or during the hospital stay addressing all of the following: activity level, diet, discharge medications, follow-up appointment, weight monitoring, and what to do if symptoms worsen.	CMS
0440	**STK-08: Stroke Education**	Proportion of ischemic or hemorrhagic stroke patients with documentation that they or their caregivers were given stroke education materials.	The Joint Commission
MIPS288	**Dementia: Education and Support of Caregivers for Patients with Dementia**	% of patients with dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND were referred to additional resources for support in the last 12 months	American Academy of Neurology

Documentation-Related Quality Measures

NQF #	Measure Title	Measure Description	Steward/ Developer
1647	**Beliefs and Values**	% of hospice patients with documentation of a discussion of spiritual/religious concerns or documentation that the patient/ caregiver/ family did not want to discuss.	University of North Carolina-Chapel Hill
0338	**CAC-3: Home Management Plan of Care (HMPC) Document Given to Patient/Caregiver**	Proportion of pediatric asthma patients discharged from an inpatient hospital stay with a HMPC document in place.	The Joint Commission
0025	**Management plan for people with asthma**	% of patients for whom there is documentation that a written asthma management plan was provided either to the patient or caregiver, or specific written instructions on under what conditions the patient’s doctor should be contacted or patient should go to the ED	IPRO
0649	**Transition Record with Specified Elements Received by Discharged Patients**	% of discharges from an ED to ambulatory care or home health care, in which the patient, regardless of age, or their caregiver(s), received a transition record at the time of ED discharge including all of the specified elements	PCPI