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# Helping Those Who Help Others

*The Modified Caregiver Strain Index.*



Ed Eckstein

**Overview:** The Modified Caregiver Strain Index can be given to family members caring for disabled older adults. It helps to determine their level of *strain*—a combination of stress and burden that has consequences on caregivers’ overall health. The index assesses 13 aspects of physical health, family finances, social interactions, time demands, and employment. By pinpointing the sources and degree of strain, the index can guide in the selection of interventions that might be used to alleviate caregivers’ strain and improve the lives of caregivers and care recipients. To watch a free video demonstrating the use of the index, go to <http://links.lww.com/A291>.



### Web Video

Watch a video demonstrating the use and interpretation of the Modified Caregiver Strain Index at <http://links.lww.com/A291>.



### A Closer Look

Get more information on why it’s important for nurses to determine family caregivers’ level of strain, as well as why the Modified Caregiver Strain Index is the right approach.



### Try This: The Modified Caregiver Strain Index

This is the approach in its original form. See page 65.



### Online Only

Unique online material is available for this article. A URL citation appears in the printed text; simply type it into any Web browser.

**S**ebastian Peters, age 80, is the primary caregiver for his 78-year-old wife, Anna, who has Alzheimer’s disease. He’s aided to varying degrees by the couple’s three children, Libby Carlson, Brenda Hoffmann, and Jim Peters, all in their 50s with jobs and families. (This scenario is a composite of several clinical cases.)

Shortly after Ms. Peters was diagnosed, the family held a meeting to arrange for her care. Ms. Carlson, who lives nearby, volunteered to stay overnight several times a week to help her father make sure her mother did not wander, which patients with dementia tend to do. As Ms. Peters’s condition declined, so did her husband’s ability to care for her—her weight decreased from 120 to 98 lbs., she was not bathing routinely and wore dirty clothes, and her poor oral hygiene caused her to lose several teeth. The family enrolled her in an adult day care program and hired home care aides. This alleviated the daily burden of Mr. Peters, who has type 2 diabetes (which is well controlled), hypertension and hyperlipidemia (both controlled with medication), and some visual

impairment as a result of diabetes. But his stress level surged when his wife fell and broke her hip, necessitating surgery.

Mr. Peters remained at his wife’s side throughout her hospitalization and subsequent stay in a rehabilitation facility. During this period Mr. Peters lost 12 lbs., slept poorly in the bed that staff provided for him, and began looking gaunt and pale to his children. Shortly after his wife’s discharge to their home, he fell and broke his wrist when responding to her urgent call. Soon thereafter, Ms. Peters was barred from the adult day care program for biting another attendee, resulting in another family meeting to discuss her needs. Ms. Peters couldn’t participate (her cognitive impairment was too advanced), and all three children said they could not adequately care for their mother in their home.

The family decided to place Ms. Peters in an assisted living facility. She adapted well, regaining the weight she’d lost, and her husband, who visits her every day, says that his health has also rebounded. “Now that I’m able to be on a schedule, my blood sugar is much better, and I’m feeling better overall,” he says.




## Why Assess for Strain in Family Caregivers?

While many family caregivers find their role to be deeply satisfying, many also neglect their own health in order to meet the needs of chronically ill family members. They can experience severe stress, and research indicates that caregivers often have health problems,<sup>4,5</sup> take more medications than noncaregivers,<sup>5</sup> and experience depression.<sup>4,6</sup>

For more information on who provides informal care to older adults and at what cost, please see the supplement to this issue of *AJN*, "State of the Science: Professional Partners Supporting Family Caregivers," also available for free online at [www.nursingcenter.com/ajnfamilycaregivers](http://www.nursingcenter.com/ajnfamilycaregivers).

### THE MODIFIED CAREGIVER STRAIN INDEX

This family's strain, resulting from the husband's and children's struggles to cope with Ms. Peters's progressing dementia, is exactly what the Modified Caregiver Strain Index was designed to appraise. Stress and burden are a caregiver's daily physical and psychological responses to caregiving. But over time, stress and burden become strain, which is a deterioration in financial, physical, psychological, and social health.<sup>1</sup> The index is an easy-to-use questionnaire that in most cases can be self-administered. Its results can be used to pinpoint the causes and degree of strain, as well as changes in strain over time, so interventions can be implemented before a caregiver's health suffers significantly. A positive response to any of the index's 13 statements should prompt more focused assessment and the implementation of strategies to address the area of stress. Such strategies may include preventive education, cognitive behavioral therapy, and counseling; they can improve the caregiver's quality of life and, by extension, the care recipient's, as well.<sup>2,3</sup> Ideally, the index is used at an early stage of caregiving to establish a baseline and again regularly over the course of the illness. It can be used in all settings. For more information, see *Why Assess for Strain in Family Caregivers?* above.<sup>4,6</sup> And to view the segment of the online video in which nurses discuss the importance of assessing strain in caregivers, go to <http://links.lww.com/A292>. 

The index targets four domains of strain: financial, physical, psychological, and social and personal. The caregiver's responses to its 13 statements establish the presence and degree of sleep distur-

bance; inconvenience; physical effort; confinement; family, personal, emotional, and employment disruption; time pressures; upset resulting from changes in patient behavior and personality; financial stress; and emotional and psychological overload.<sup>1</sup>

Evaluation should not be limited to the primary caregiver. Other family members and informal caregivers such as friends or neighbors, based on nurses' judgment, are candidates for assessment even if they provide only intermittent help to the primary caregiver. In the case of the Peters family, giving the questionnaire to Mr. Peters and each of his children soon after Ms. Peters was diagnosed would have provided valuable baseline information. The nurse in Ms. Peters's primary care setting could then have reevaluated the level of strain when circumstances changed. For example, when Ms. Peters began wandering during the night and her husband and daughter took turns staying up to monitor her, the index could have provided a basis for guiding the family to helpful community resources. It also might have been useful to her hospital nurses at three points during the treatment of Ms. Peters's broken hip—in the ED, on the medical-surgical unit, and on the rehabilitation unit—in helping Mr. Peters to maintain his health during that stressful period.

*The index is used to establish a baseline and again regularly over the course of the illness.*

Results from administration of the index can also augment medical records, providing clinicians with information about a caregiver's abilities. For example, data from the index could have accompanied Ms. Peters's hospital and rehabilitation records when they were forwarded to her primary care provider and adult day care program. Results can be updated when a caregiver's status changes significantly—for example, when Mr. Peters fractured his wrist.

### ADMINISTERING THE INDEX

Nurses should explain before administering the index that a family member's chronic illness is difficult for both the patient and family members. The nurse



# try this: **Best Practices in Nursing Care to Older Adults**

from **The Hartford Institute for Geriatric Nursing**  
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New York University College of Nursing

## The Modified Caregiver Strain Index (CSI)

By M. Terry Sullivan, RN, MSW, MSN, CMC, Connecticut Community Care, Inc.

**WHY:** Informal supporters provide the majority of long-term care to chronically disabled older adults. Caregiving has been recognized as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue, and changes in social relationships. They may also experience physical health problems. Perceived caregiver burden has been associated with premature institutionalization and patient reports of unmet needs. Screening tools are useful to identify families who would benefit from a more comprehensive assessment of the caregiving experience.

**BEST TOOL:** The Modified Caregiver Strain Index (CSI) is a tool that can be used to quickly screen for caregiver strain with long-term family caregivers. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social, and Time. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. The Modified Caregiver Strain Index is a version of the Caregiver Strain Index developed in 1983. The tool was modified and developed in 2003 with a sample of 158 family caregivers providing assistance to adults aged 53 and older living in a community-based setting (Travis, et al, 2002; Thornton & Travis, 2003). Scoring is 2 points for each 'yes', and 1 point for each 'sometimes' response. The higher the score, the higher the level of caregiver strain.

**VALIDITY AND RELIABILITY:** Internal reliability coefficient is slightly higher ( $=.90$ ) than the coefficient originally reported for the CSI in 1983 ( $=.86$ ). Two-week retest data for one-third of the caregiving sample ( $n=53$ ) were available and resulted in a test-retest reliability coefficient of  $.88$ .

**STRENGTHS AND LIMITATIONS:** The Modified CSI is a brief, easily administered, self-administered instrument. Long-term family caregivers were not comfortable with the dichotomous choice on the CSI and the modified instrument provides the ability to choose a middle category response best suited to some situations. The Modified CSI clarifies and updates some of the items on the original instrument. The tool is limited by lack of a corresponding subjective rating of caregiving impact. There is no breakdown of score regarding low, moderate or high caregiver strain, so professional judgment is needed to evaluate by total score the level of caregiver strain. The tool effectively identifies families who may benefit from more in-depth assessment and follow-up.

**FOLLOW-UP:** The higher the score on the Modified CSI, the greater the need for more in-depth assessment to facilitate appropriate intervention. Additional items and further efforts to develop and test a set of subscales could enhance the applicability of the instrument for research and practice. The patient's cognitive status and problematic behaviors should be assessed, as well as the caregiver's perception of role overload or deprivation in key relationships, goals or activities. Family conflict, work role-caregiving conflict, and caregiver social support are also important variables in the overall caregiving experience. Additional work with highly strained long-term caregivers who are receiving little or no formal services is indicated.

### MORE ON THE TOPIC:

Best practice information on care of older adults: [www.ConsultGerRN.org](http://www.ConsultGerRN.org).

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# Modified Caregiver Strain Index

**Directions:** Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
<b>My sleep is disturbed</b> (For example: the person I care for is in and out of bed or wanders around at night)	_____	_____	_____
<b>Caregiving is inconvenient</b> (For example: helping takes so much time or it's a long drive over to help)	_____	_____	_____
<b>Caregiving is a physical strain</b> (For example: lifting in or out of a chair; effort or concentration is required)	_____	_____	_____
<b>Caregiving is confining</b> (For example: helping restricts free time or I cannot go visiting)	_____	_____	_____
<b>There have been family adjustments</b> (For example: helping has disrupted my routine; there is no privacy)	_____	_____	_____
<b>There have been changes in personal plans</b> (For example: I had to turn down a job; I could not go on vacation)	_____	_____	_____
<b>There have been other demands on my time</b> (For example: other family members need me)	_____	_____	_____
<b>There have been emotional adjustments</b> (For example: severe arguments about caregiving)	_____	_____	_____
<b>Some behavior is upsetting</b> (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)	_____	_____	_____
<b>It is upsetting to find the person I care for has changed so much from his/her former self</b> (For example: he/she is a different person than he/she used to be)	_____	_____	_____
<b>There have been work adjustments</b> (For example: I have to take time off for caregiving duties)	_____	_____	_____
<b>Caregiving is a financial strain</b>	_____	_____	_____
<b>I feel completely overwhelmed</b> (For example: I worry about the person I care for; I have concerns about how I will manage)	_____	_____	_____

[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

**Total Score =**

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences*, 58(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.



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## Watch It!

Go to <http://links.lww.com/A291> to watch a nurse use the Modified Caregiver Strain Index to determine caregivers' levels of strain and discuss how to administer it and interpret results. Then watch the health care team plan preventive strategies.

View this video in its entirety and then apply for CE credit at [www.nursingcenter.com/AJNolderadults](http://www.nursingcenter.com/AJNolderadults); click on the *How to Try This* series link. All videos are free and in a downloadable format (not streaming video) that requires Windows Media Player.

should understand that caregiver strain increases the risk of burnout, potentially leading to premature institutionalization of the patient.<sup>1</sup> When given regularly (perhaps annually), the index can be used to help monitor the continuing effects of caregiving on family members.

Family members may wonder why they are being asked periodically to fill out the questionnaire. The Peters family, for example, might have been told, "As we've discussed, dementia is a chronic illness that influences everyone in the family. We'd like each of you to fill out this questionnaire, the Modified Caregiver Strain Index. And because dementia symptoms worsen over time, we'll be asking you to complete the questionnaire at least once a year, so we can work with you to identify ways to alleviate your strain." Such a dialogue can continue with family members regardless of the setting: physician's office, hospital, adult day care program, assisted living facility, nursing home, or patient's home.

### SCORING AND INTERPRETATION

The response to each of the index's 13 statements receives a numerical score; yes, on a regular basis = 2; yes, sometimes = 1; and no = 0. The caregiver checks the line that best describes her or his situation. The nurse tallies the marks in each column and multiplies by the corresponding value (2, 1, or 0). The nurse then adds these subtotals to obtain a total score. Scoring ranges from 0 to 26, with 0 indicating no caregiver strain and 26 indicating extreme strain. To see the portion of the online video that shows a nurse expert discussing the index and why it's important to use, go to <http://links.lww.com/A293>.

For hypothetical results of the Peters family's strain assessment at the time of Mr. Peters's fall and broken wrist, go to <http://links.lww.com/A516>. The scores show the husband to be suffering from extreme strain, closely followed by the daughter who's his main backup. The other two children also show evidence of strain, but not to the same degree.

### CHALLENGES TO USING THE INDEX

The index doesn't take long to administer, but it does require nurses to adopt a proactive approach to chronically ill patients and their caregivers, placing an emphasis on prevention. Support from administrators and institutional policy-setting committees also is needed.<sup>7,8</sup> Another challenge for institutions using health-promoting evidence-based protocols is securing reimbursement for the extra time, effort, and skill these protocols require.

In addition, the ways in which caregivers express strain can vary and may depend in part on ethnic

and cultural influences.<sup>9</sup> Dilworth-Anderson and colleagues examined the health of 107 black caregivers of older adult family members over three years to assess the degree to which caregiving was influenced by cultural values.<sup>10</sup> They defined this basis for caregiving as "cultural justification"; for example, one such reason cited was "By giving care to elderly dependent family members, I am giving back what has been given to me." They found that caregivers with moderate cultural justification showed "higher psychosocial health" after three years than did those with weak or strong cultural justification. The researchers posited that those with strong cultural justification might feel trapped by a sense of duty and that those with little cultural justification might lack alternatives.

Tang and colleagues found more depressive symptoms among 170 Taiwanese family caregivers of patients dying of cancer than did researchers studying caregivers from Western cultures.<sup>11</sup> They theorized that Taiwanese culture's emphasis on family duty and parental authority may have exacerbated their subjects' stress.

Gallagher-Thompson and colleagues noted that Latinos older than age 65, the fastest-growing population in the United States, are projected to number 12.5 million by 2050, 4.5 million of whom will require long-term care.<sup>12</sup> The researchers also found that Latino caregivers of older adults tend to be younger members of the "sandwich generation" and to have more children living at home and a lower income than white caregivers of older adults.

Nurses who work predominantly with non-English-speaking populations may find it valuable to translate the index into their patients' languages. Similarly, nurses working with low-literacy populations may want to administer the index by interview. After identifying areas of strain, nurses should collaborate with caregivers to develop culturally appropriate interventions.<sup>12</sup>

### COMMUNICATING FINDINGS

Discussing the results gives nurses an opportunity to evaluate caregivers' strain over time and the degree to which interventions have helped. Holding this



### Online Resources

For more information on this and other geriatric assessment tools and best practices go to [www.ConsultGeriRN.org](http://www.ConsultGeriRN.org)—the clinical Web site of the Hartford Institute for Geriatric Nursing, New York University College of Nursing, and the Nurses Improving Care for Healthsystem Elders (NICHE) program. The site presents authoritative clinical products, resources, and continuing education opportunities that support individual nurses and practice settings.

Visit the Hartford Institute site, [www.hartfordign.org](http://www.hartfordign.org), and the NICHE site, [www.nicheprogram.org](http://www.nicheprogram.org), for additional products and resources.

Go to [www.nursingcenter.com/AJNolderadults](http://www.nursingcenter.com/AJNolderadults) and click on the *How to Try This* link to access all articles and videos in this series.

discussion in a private environment will allow caregivers to be candid.

Ideally, the nurse should meet with each caregiver alone for 15 to 30 minutes and then gather all of the caregivers for a 15-minute group discussion. With the Peters family, this would take about an hour and a half. (While investing time in private and group discussion is valuable, it might not always be practical or even necessary; each family should be treated according to its needs.) If a caregiver is found to have strain, it is appropriate for the nurse to ask if she or he can notify the primary care provider. The nurse might evaluate the health and living situation of the care recipient as well. In addition, interventions for caregivers might include referral to family or individual counseling or to a caregiver support group.<sup>2</sup> Other interventions, depending on the area of strain, might include referral to a sleep clinic, financial planner, home health care provider, or housecleaning service.

An open-ended interview strategy works best when talking with caregivers about results. To the elder Mr. Peters the nurse might say, “You have been through a great deal recently. How are you doing?” Then, to focus the conversation: “Your overall score on the Modified Caregiver Strain Index is 22 out of 26, which confirms that you are experiencing extreme strain. You scored a 2 in almost every category. What do you think would help make things easier on you?” In this way, the conversation moves to problem solving.<sup>2,13</sup>

The same procedure could then be used with each of the adult children. In the group meeting the

nurse might say: “I can tell that each of you loves Ms. Peters a great deal and wants her to receive the best care possible; each of you also has a number of pressures in your life in addition to her dementia. We’ve discussed a plan to help each of you with the strain of caregiving. What thoughts do you have about how you can help one another?”

#### CONSIDER THIS

How is the Modified Caregiver Strain Index different from its precursor, the Caregiver Strain Index? In 1983 Robinson developed the original index, which required yes-or-no responses.<sup>14</sup> Subsequent research found that older adult caregivers who’d been providing care for extended periods did not like being limited to a yes-or-no response,<sup>1,15</sup> so a “sometimes” option was added in the modified index. The statements also have been reworded to elicit more precise evidence of strain and its sources.<sup>1</sup>

What is the reliability of the modified index? Thornton and Travis reported a high internal reliability coefficient of 0.9 for a sample of 158 family caregivers.<sup>1</sup> A test–retest reliability coefficient of 0.88 for a two-week period was obtained on 53 of the subjects, indicating that the tool is highly stable.

What is the validity of the modified index? Thornton and Travis found that a caregiver’s strain as measured by the index correlated significantly ( $P < 0.001$ ) with the care recipient’s mental capacity ( $r = 0.34$ ), level of functional ability ( $r = 0.27$ ), and combined capacity of mental and physical functioning ( $r = 0.32$ ).<sup>1</sup> This means that as the care recipient’s functioning declined, the caregiver’s strain increased. Thornton and Travis also evaluated concurrent validity by comparing two other instruments to the modified index. The Family Caregiver Medication Administration Hassles Scale correlated with the index scores ( $r = 0.44$ ;  $P = 0.001$ ), indicating that “hassles” in medication administration were associated with caregiver strain. ▼

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**GENERAL PURPOSE:** To instruct registered professional nurses in the use of the Modified Caregiver Strain Index to help family members determine their level of strain, a combination of stress and burden, that can affect caregivers' overall health.

**LEARNING OBJECTIVES:** After reading this article and taking the test on the next page, you will be able to

- discuss the background information helpful in understanding the need for assessing caregiver strain.
- outline the appropriate use of the Modified Caregiver Strain Index.
- summarize the development and outcomes of the Modified Caregiver Strain Index.

### TEST INSTRUCTIONS

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