



Montana Geriatric Education Center

Instructions on Completing the Module

Assessment of Caregiver Strain

**The results of the assessments and evaluations are confidential, and the data is used to meet requirements of our federally funded grant.*

Please make sure to turn in Pre-Test, Post-Test, and Module Evaluation.

1. **Before** reading the module, and without looking at it, complete the Pre-Test. Record your answers on the examination form marked Pre-Test. (*Found at the start of the module.*) Keep the completed answer form to turn in at the completion of the module.

2. Complete the module as outlined.

3. **After** reading the module and watching the videos, please complete the Post-Test. Use the questions in Appendix **D** and record your answers on the examination form marked Post-Test. (*Found at the end of Appendix D.*) Keep the completed answer form to return with the pre-test at the completion of the module.

Complete the Module Evaluation. (*Appendix E, found after the post-test.*) Keep the completed module evaluation form to return with the pre-test and post-test at the completion of the module.

4. **To obtain credit for the module you must:**
 - a. Complete [online](#) or return the MTGEC Participant Profile
 - b. Turn in the Pre-Test, Post-Test, and Module Evaluation
 - c. Obtain a score of 70% or better on the Post-Test

MTGEC/IPHARM

Skaggs Building Room 318
University of Montana
32 Campus Drive
Missoula MT, 59812-1522

Email: IPHARM@umontana.edu

Phone (406) 243-2339 & Fax (406) 243-435

Pre-test: *Assessment of Caregiver Strain*

Record responses on examination form.

1. What percentage of unpaid care provided to older adults is provided by family members?
 - a. 25 %
 - b. 50%
 - c. 60%
 - d. 85%

2. The most accurate definition of *caregiver strain* is?
 - a. An individual's physical and/or emotional response to challenges in the caregiver role.
 - b. The caregiver's perception of enduring problems or an altered state of well-being.
 - c. The burden experienced when a caregiver is providing intensive care (greater than 21 hours a week).
 - d. The physical and psychological outcomes experienced by a caregiver who provides extensive and prolonged care.

3. The pathophysiology of caregiver strain includes
 - a. Autonomic disruptions and changes in the diurnal rhythm of the HPA axis.
 - b. Decreased cortisol levels secreted by the adrenal cortex.
 - c. A shift to high morning and decreased evening cortisol levels.
 - d. A physical response to chronic stress that does not include changes in emotional health.

4. Findings from the Alzheimer's Association (2015) indicated that
 - a. 59% of caregivers reported high or very high emotional stress with caregiving.
 - b. 59% of caregivers reported high or very high physical stress with caregiving.
 - c. The number of hours of caregiving directly affects self-reported caregiver strain.
 - d. In the last year of caregiving 35% of caregivers reported they were "on duty" 24 hours a day.

5. Which of the following characteristics was NOT found to be positively correlated with being a caregiver in American Indian communities?
 - a. Participant in traditional healing events
 - b. Large family size
 - c. Younger female
 - d. Socio-economic status

6. Self-reported benefits of informal family caregiving have included all listed EXCEPT
 - a. Developing personal strength and aging readiness
 - b. Resolving past hurts and conflicts
 - c. Experiencing the older person's full life (here and now and there and then)
 - d. Preserving financial resources for providing care themselves

7. Which statement is INCONSISTENT with the Healthy Caregiver Hypothesis?
 - a. Coping with mild levels of stress has been found to be physiologically and psychologically protective.
 - b. Feelings of self-efficacy and reliance may result from coping with mild levels of stress.
 - c. The intensity and duration of caregiving are main factors in the health of the caregiver.
 - d. There may be time-sensitive health benefits related to a caregiving episode.

8. Which of the following statements is most appropriate for the administration of the MCSI?
 - a. The directions are self-explanatory and there is no need to converse about the need for the screening.
 - b. Since the possible responses are "yes" or "no" to the 13 items this makes scoring simple.
 - c. The MCSI was designed to screen only immediate caregivers.
 - d. The MCSI was designed to be administered at different points in time to monitor continuing effects of caregiving.

9. Appropriate follow-up for caregivers who score high on the MCSI include:
 - a. The care recipient's cognitive status and behaviors
 - b. The caregiver's perception of role overload or deprivation in relationships, goals or activities
 - c. The work-role and caregiving conflict
 - d. All of the above

10. When discussing results of the MCSI with caregivers it is recommended that
 - a. Health care professionals start with an open-ended interview strategy
 - b. Health care professionals gradually ask more focused questions leading to "What may make things easier for you?"
 - c. Health care professionals move the discussion to problem solving while discussing the key items on the MCSI where the caregiver reports strain
 - d. All of the above

PRE-TEST: Examination Form
Assessment of Caregiver Strain

Participant Information

1. Name: _____
2. Mailing address: _____

3. Date exam completed _____

Questions: (Please circle one response per question)

1	A	B	C	D
2	A	B	C	D
3	A	B	C	D
4	A	B	C	D
5	A	B	C	D
6	A	B	C	D
7	A	B	C	D
8	A	B	C	D
9	A	B	C	D
10	A	B	C	D

For credit, please return this completed page to:

MTGEC/IPHARM
 Skaggs Building Room 318
 University of Montana
 32 Campus Drive
 Missoula MT, 59812-1522
 Phone (406) 243-2339 & Fax (406) 243-4353



Montana Geriatric Education Center

Assessment of Caregiver Strain

Allison Duffy, RN, MN Montana Tech
Nursing Program

Montana Geriatric Education Center

A 2-hour Geriatric Health Screening Module from the

Montana Geriatric Workforce Enhancement Program

A Consortium of: University of Montana,

Missoula

Mountain Pacific Health, Helena

RiverStone Health, Billings

St. Vincent Healthcare, Billings

[Montana Geriatric Education Center Website](#)

February 2017

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Montana Geriatric Education Center

MONTANA GERIATRIC EDUCATION CENTER (MTGEC)

Assessment of Caregiver Strain

Disclosures

Montana Geriatric Workforce Enhancement Program Goals/Purpose

Improve health outcomes for older adults in rural Montana via increased knowledge of older adult care and treatment of health problems by health professionals.

Successful Completion of this Continuing Education Activity:

1. Completion of Pre-Test
2. Reading of text and associated website resources
3. Viewing the Hartford caregiver strain video
4. Completion of Post-Test with at least 70% accuracy
5. Completion of module evaluation

Contact Hours: 2

Montana Nurses Association (MNA)

The Montana Geriatric Education Center is an approved provider of continuing nursing education by the Montana Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

MNA Continuing Nursing Education Expiration Date: 2/21/2020

Conflicts of Interest

The planners and presenters of the CE activity have disclosed no relevant financial relationship with any commercial companies pertaining to this activity.

The Montana Geriatric Workforce Enhancement Program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U1QHP28733, Geriatric Workforce Enhancement Program (GWEP); the total award is \$2,143,140 and supports the program 100%. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Description of Module

Content:

Increasingly, family and informal caregivers are providing significant care for an aging population. For some caregivers, this is associated with perceived strain and possible negative health outcomes. The Modified Caregiver Strain Index (MCSI) is discussed as a tool which can screen caregivers over time and across the health care continuum. The tool can be administered and interpreted by health care providers from multiple disciplines so that appropriate referrals for follow up and support can be included in the plan of care.

Module Purpose:

Upon completion of the module, learners will demonstrate improved knowledge of screening techniques to identify caregiver strain in older adults and provide counseling and/or follow-up resources.

Learning Objectives:

Specifically the learner will be able to:

1. Evaluate current research findings related to the prevalence and assessment of caregiver strain.
2. Discuss the development of the Modified Caregiver Strain Index (MCSI).
3. Utilize the Modified Caregiver Strain Index (MCSI) in clinical practice.

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Assessment of Caregiver Strain

I. Overview of Caregiving

Caregiving is a universal phenomenon which can take many forms and is central to the survival of society. The term caregiver is often associated with family caregiving which is broadly defined as one who provides care to a family member or relative, partner, or a friend (Reinhard, Feinberg, Choula & Houser, 2015). An aging society, increased prevalence of chronic diseases, and higher levels of disability have all converged in a time of rising health care costs and rapidly changing health care policy. Of particular importance is the role family caregiving plays in the viability of the U.S. health and long-term care services systems (Reinhard, Feinberg, Houser, & Choula, 2011). The literature on this topic has referred to family caregivers as both “invaluable” and also “invisible” (Reinhard, Feinberg, Choula, & Houser, 2015; Brodaty & Donkin, 2009).

In 1987 former First Lady Rosalynn Carter was recognized in the formation of the Rosalyn Carter Institute for Caregiving on the campus of Georgia Southwestern State University (Rosalyn Carter Institute for Caregiving, 2012). The organization’s expressed commitment was to encourage support for caregivers by enhancing their health and resilience through local, state, and national long-term care programming. The institute conducted studies of caregiving experiences and evidence-based programs which were designed to assist unmet needs in the caregiving process. By 2010 the institute provided a position paper which outlined 12 recommendations to “avert the caregiving crisis” (Rosalyn Carter Institute for Caregiving, 2012, p. 2). Key players included in

the dialogue were the Centers for Medicare and Medicaid, the Department of Health and Human Services, the Department of Labor, the U.S. Department of Veterans Affairs, the Administration on Aging, and the Social Security Administration (Rosalyn Carter Institute for Caregiving, 2012). The central interest of these large agencies on the issue of family caregiving was best explained by Assistant Secretary of Aging Kathy Greenlee. At the institute's 2010 summit she stated, "Families are the core of the system. They always have been. They are both the center and the soul of the system. We need family caregivers--we need them because there is no replacement. You can't buy this commodity. But we also need them economically as a nation, because we can't afford to buy this care from strangers." (Rosalyn Carter Institute for Caregiving, 2012, p. 2).

A. Invisible Caring

Family caregivers have been recognized fairly recently as invaluable in the long-term care system. As stated previously, they also provide invisible care that may not be recognized by either health care providers or policy makers. Indeed, eighty-five percent of the unpaid care for older adults is provided by family members (Alzheimers Association, 2015). A definition of caregiving includes a description of the activities which are performed by informal (mostly unpaid) care providers. These activities include assistance with personal care, bathing, dressing, cooking/meal preparation, shopping, bill paying, assistance with insurance forms, and transportation. Additionally, family caregivers may perform delegated medical and nursing tasks such as medication administration, wound care, infusions, injections, and increasingly complex home care treatment plans. Family caregivers often have a main responsibility of

advocating and communicating for the care recipient during health care appointments and hospitalizations (Reinhard, Feinberg, Choula, & Houser, 2015). Clearly, this wide array of caregiver tasks has the potential to add up to many hours over time. Having multiple formal health care providers and a complex informal care situation may lead to the full extent of the care provided remaining unrecognized.

B. Invaluable Caring

To quantify the family caregiving which occurs in the U.S., the AARP Public Policy Institute (2015) provided some numbers in both hours and dollars to give recognition to the invaluable and invisible aspects of family caregiving. Forty million family caregivers in the U.S. provided 37 billion hours of care in 2013. The cost of this care was calculated to be \$470 billion dollars, just slightly less than Walmart's annual sales in 2013-2014, but more than the combined annual sales of Apple, IBM, Hewlett Packard and Microsoft in the same time period (AARP Public Policy Institute, 2015). Additionally, unpaid informal caregiving was calculated to exceed the value of paid home care plus total Medicaid spending in the same year (AARP Public Policy Institute, 2015).

The 2014 "Caregiving in the U.S" survey (AARP, 2015) also provided a state-by- state breakdown of the number of caregivers and the economic value of caregiving. For example, the state of Montana with a population of 1,202,000 included 118,000 caregivers and 110 million care hours for the year (2013-2014). The economic value of 1 hour of care was estimated from the state's minimum wage, and the median wage of a home health aide or private pay home

care worker. For Montana this was valued at \$12.97 per hour, resulting in a total economic value of \$1,430,000,000 in 2013 (AARP Public Policy Institute, 2015). The average caregiver spends at least 18 hours per week in caregiving tasks, and most family caregivers provided this care while working full or part-time (AARP Public Policy Institute, 2015).

A definition of intensive caregiving (providing 21 or more hours of care per week) was provided by the National Alliance for Caregiving (2015). This characterizes 22% of all caregivers who, at the same time, work at a job. Furthermore, 68 percent of family caregivers used their own money to provide care and 39 percent expressed that this caused financial strain (AARP Public Policy Institute, 2015). Perhaps the most important finding in the 2014 survey was the 55 percent of all caregivers who reported they felt overwhelmed by the amount of care needed for a family member (AARP Public Policy Institute, 2015).

II. Definitions of Caregiver Burden, Stress and Strain

Prior to the recent focus on financial implications of family caregiving, there was a developing body of research which focuses on variety of experiences of family caregiving. A conceptual challenge with discussing this topic is the definitions of terms. The terms caregiver burden, stress, and strain are often used equally and interchangeably in the literature (Thorton & Travis, 2003). The terms “burden” and “stress” have been defined as “an individual’s physical and/or emotional response to challenges in the caregiver role” (Thorton & Travis, 2003, p. S127). The term “strain” is defined as “the caregiver’s perception of enduring problems or an

altered state of well- being” (Thorton & Travis, 2003, p. S127). It has been shown consistently that four out of ten caregivers experience high strain, and this results in lower life satisfaction and health related quality of life measures (Dahlrup, Ekstrom, Nordell, & Elmstahl, 2015; Palos, Mendoza, Liao, Anderson, Gonzalez, Haahn,...Cleeland, 2011).

The North American Nursing Diagnosis (NANDA) committee defined *Caregiver Role Strain* as “A state in which an individual is experiencing physical, emotional, social, and/or financial burden(s) in the process of giving care to another” (Carpenito-Moyet, 2010, p. 65). Defining characteristics, related factors (including pathophysiologic and treatment-related), and situational factors (personal and environmental) have been defined and are presented in Table 1.

Table 1: Caregiver Role Strain

Defining Characteristics (Expressed or Observed)	Related Factors (Pathophysiologic and Treatment Related)	Situational (Personal and Environmental)
<ul style="list-style-type: none"> • Reports insufficient time/energy • Difficulty performing caregiving activities • Interferes with other roles (work, spouse, friend, parent) • Apprehension about the future related to abilities • Depressed feelings, anger • Feelings of exhaustion • Feelings of resentment 	<ul style="list-style-type: none"> • Debilitating conditions (both acute and progressive) • Progressive dementia • Disability • Chronic mental illness • Unpredictable illness course • Addiction 	<ul style="list-style-type: none"> • Unrealistic expectations of caregiving by care receiver • Ineffective coping • Compromised physical health • Unrealistic expectations of self • Poor relationship/family dysfunction • Unrealistic expectations of caregiver by others (society and family) • Duration of caregiving • Isolation • Insufficient respite/recreation • Insufficient finances • Unavailable support

Adapted from Carpenito-Moyet, L.J. (2010). *Handbook of nursing diagnosis*. Lippincott Williams & Wilkins: Philadelphia (p. 65-67).

An example of a nursing diagnosis of caregiver role strain would be the following: *Caregiver Role Strain* related to expressed feelings of exhaustion (Defining Characteristics) due to frequent night-time awakenings of spouse (Related Factors) secondary to insufficient respite (Situational). Clearly, the diagnosis of care-giver role strain is a unique manifestation in every family and caregiving experience. As will be discussed later, one of the key elements of caregiver role strain is the caregiver's appraisal of their lived experience. The diagnosis of caregiver role strain can change over time as situational and related factors (such as disease progression, duration of caregiving, and available social support) take various trajectories during the caregiving experience. Thus, caregiver role strain needs to be monitored over time.

III. Health Ramifications of Caregiver Strain

Bevens and Sternberg (2012) described the effect that chronic stressors have on poor health in caregivers. It was asserted that caregiving stressors stimulate the adrenergic sympathetic nervous system (SNS) and the hypothalamic-pituitary-adrenal (HPA) axis. In this feedback system the hypothalamus releases corticotropin-releasing hormone (CRH) which then acts on the pituitary gland to secrete adrenocorticotrophic hormone (ACTH) which then acts on the adrenal cortex to secrete glucocorticoids (cortisol) (Bevens & Sternberg, 2012). Increased cortisol increases blood glucose, delays wound healing, encourages peptic ulcers, and decreases the inflammatory and immune responses (Van Meter & Hubert, 2014).

Simultaneously, the adrenal medulla releases epinephrine (adrenalin) and the sympathetic nerves release norepinephrine (Bevens & Sternberg, 2012). In combination, an increase in these hormones raises blood glucose and blood pressure, while reducing kidney function (VanMeter & Hubert, 2014). This combination produces the “fight or flight” stress response which affects many organs and cells throughout the body (Bevens & Sternberg, 2012). The stress response, when experienced chronically, can over time result in autonomic disruptions and changes in the diurnal rhythm of the HPA axis. The result is a shift to low morning and elevated evening cortisol levels which is opposite the usual diurnal pattern (Bevens & Sternberg, 2012). This shift appears to be in response to chronic stress and strain which can then affect both physical and emotional health on a long term basis.

IV. Risks and Protective Factors Related to Caregiver Strain

A. Mortality Studies

In a landmark study, Schultz and Beach (1999) reported on the results of the Caregiver Health Effects Study. The prospective population-based cohort study (1993-1998) included 392 caregivers and 427 non-caregivers aged 66 to 96 years who lived with their spouses and were followed for an average of 4.5 years. The samples were controlled for sociodemographic factors, clinical, and sub-clinical cardiovascular disease at the start of the study. Members of the sample were assessed for caregiving activities by asking them if they assisted in 6 activities of daily living and 6 instrumental tasks of daily living. For each caregiving task in which they assisted, they

were queried to see if they felt emotional or physical strain using three categories of responses (“no strain,” “some strain,” and “a lot of strain.”). Four groups emerged in analysis which included a spouse not disabled (control group), spouse disabled but not being helped, spouse disabled and helped but not reporting strain, and disabled spouse being helped and reported caregiver strain.

Major findings of the study indicated that caregivers under a lot of strain experienced a significantly increased (63 percent) mortality rate when compared to non-caregiving controls. Caregivers who were not under strain and those who did not provide care did not have increased adjusted mortality rates (Schulz & Beach, 1999). These findings suggested that caregivers may or may not be under strain and that further research was warranted in understanding this phenomenon. It also suggested that those who do experience caregiver strain suffer in their quality of life and/or die and this ultimately affects the lives of the care recipients. Limitations of the study included a mostly Caucasian sample who were spouses to the care recipients and were not representative of other caregiving arrangements, such as care provided by adult children and friends (Schulz & Beach, 1999).

Using data from the REGARDS study (REasons for Geographic and Racial Differences in Stroke) (Howard et al., 2005), a national population-based longitudinal study (n=30,239), Perkins, Howard, and Wadley et al. (2013) studied a racially representative cohort of over 3,700 (12.3%) people (not necessarily spouses) who reported caregiving activities. The study excluded subjects who had a cancer with chemotherapy diagnosis and also those who were in a nursing home or on a waiting list. Respondents reporting higher strain were more likely

to be Caucasian and female. Mortality rates were two times higher in the group reporting the highest level of strain (Perkin, Howard, & Wadley, et al., 2013). An unexpected finding was that the group reporting some strain actually had a slightly lower mortality rate than those reporting no strain (Perkin, Howard, & Wadley, et al, 2013). Fredman, Lyons, and Cauley et al. (2015) more recently reported that mortality rates of current caregivers were not significantly higher than non-caregivers, but that there may be a lag-time effect after the caregiving experience terminates. One possibility is that current caregivers may be self-selected in family systems when they are healthier than others in the family (McCann, Hebert, Bienias, Morris, & Evans, 2004).

B. Predictors and Protectors of Caregiver Strain

A Healthy Caregiver Hypothesis, similar to the healthy worker phenomenon, has been postulated where there may be some time-sensitive health benefits related to caregiving, even when there is some reported strain (Fredman, Lyons, & Cauley, 2015). Coping with mild levels of stress has been found to be both physiologically and psychologically protective, possibly by leading to feelings of self-efficacy and resilience (Lewitus & Schwartz, 2009). As previously stated, Perkins, Howard, and Wadley et al. (2013) reported the unexpected finding that caregivers who report “some strain” when compared to caregivers who report “no strain” actually experience a lower mortality rate. Clearly, there is a balance between the negative health effects of high strain caregiving and the possible positive effects of caregiving when there is some reported strain. Perkins, Howard, and Wadley et al. (2013) emphasized that the

appraisal of strain by the caregiver is more important than the relationship to the care recipient (spouse versus non-spouse) (Christakis & Allison, 2006), and the intensity and duration of caregiving (Brown, Smith, Schulz, et al., 2009) in terms of predicting factors relating to increased mortality. This finding is consistent with the pioneering work of Schultz and Beach (1999).

Brodaty and Donkin (2009) summarized variables which have been presented in the literature as they related to greater strain versus lower strain and psychological morbidity. The authors referred to studies which suggested predictors and protectors from caregiver distress. Past findings suggested female spouses who live with the care recipient and had lower incomes fit the demographic description of those with greater strain. The duration of caregiving has not shown significant differences in caregiver strain. The presence of dementia combined with behavioral disturbances and impairment in basic activities, especially incontinence, led to greater strain as opposed to caring for recipients who have maintained more functional ability. Poorer relationships and lack of past and current intimacy were associated with more caregiver strain. Holding a perception of being trapped in the caregiver role or having a low sense of confidence of their ability in the caregiver role were associated with more caregiver strain when compared to caregivers who reported a feeling of higher competence in the role (Brodaty & Donkin, 2009, p. 221).

C. Caregiving for family members with dementia

There is a separate and extensive body of research surrounding family care of dementia sufferers. Dementia, which is most likely Alzheimer's disease, is growing in prevalence along

with an aging population. The Alzheimer's Association (2016a) has listed Montana, along with several other western states including Wyoming, Idaho, Alaska, Nevada, Arizona, and New Mexico as leading the nation in the projected rate of growth of persons aged 65 and over who will have Alzheimer's disease. The projected rate of increase is in the range of 41-61 percent between 2016 and 2025 (Alzheimer's Association, 2016a). The most recent data regarding Montana indicates that in 2015 there were 49,000 persons who cared for a person suffering from Alzheimer's or another dementia. The caregivers provided 55,000,000 hours of unpaid care with an economic value of \$679,000,000. The higher health care costs attributed to caregiving in Montana was an estimated \$30,000,000 (Alzheimer's Association, 2016b). One in nine older Americans suffers from Alzheimer's disease with 81 percent of cases diagnosed in those 75 years and older. For those 85 years and older the prevalence is 32 percent (Alzheimer's Association, 2015). Twice as many caregivers have reported substantial emotional, physical, and financial difficulties when compared to caregivers of people without dementia (Alzheimer's Association, 2015).

In addition to the caregiving tasks mentioned earlier, the care of dementia patients is characterized by nearly round the clock care as the disease progresses. As people with dementia approach the last year of their life, 59 percent of caregivers report that they felt "on duty" 24 hours a day (Alzheimer's Association, 2015). One facet of the care of dementia patients is the potential for wandering, safety concerns, confusion and sometimes explosive behaviors. Dementia caregivers also report frequent sleep disturbances. Data from the Alzheimer's Association (2015) also demonstrated that high or very high levels of emotional

stress were reported in 59 percent of caregivers whereas only 38 percent reported that the physical stress of caregiving was rated as high or very high. Aneshensel, Pearlin, Mullan, Zarit, and Whitlach (1995) noted that it appears it is high caregiver strain (as appraised by the caregiver), and not caregiving per se, that has deleterious effects on the physical and emotional health of the caregiver. Research findings reported over the last twenty years makes this observation quite relevant.

V. Culture and Caregiving

It is important to consider cultural factors when discussing caregiver role strain. In the U.S., whites (non-Hispanic) have the lowest prevalence rate of caregiving for a person 50 years or older (16.9 percent). Asian Americans have a 19.7 percent prevalence rate, while African Americans and Hispanics top the groups at 20.3 and 21.0 percent respectively (National Alliance for Caregiving, 2015). Pinquart and Sorenson (2005) provided results of a meta-analysis of over a hundred studies and found that all ethnic minorities reported poorer health with caregiving and a lower socioeconomic status than non-Hispanic whites. Minority groups reportedly relied on family and friends in addition to care provided by close family, a pattern that was not seen in non-Hispanic white caregivers (Pinquart & Sorenson, 2005).

Dilworth-Anderson, Brummett, Goodwin, Williams, & Siegler (2005) studied African American caregivers who provided care to elders and compared them to a group of non-Hispanic whites using a Cultural Justifications for Caregiving Scale. The results indicated that African American women scored the highest on the scale while also reporting less caregiver

strain and depression than non-Hispanic whites (Dilworth- Anderson, Brummett, Goodwin, Williams, & Siegler, 2005). Asian Americans and Hispanics have been found to have higher rates of both caregiver strain and depression when compared to non-Hispanic whites (American Psychological Association, 2016).

In a study of adult caregiving among American Indians it was found there was a 17 percent caregiving rate from a study sample of over 5,000 within two Lakota Sioux tribes and one southwestern tribe. Positively correlated with being a caregiver were younger age, female, a large household, and a participant in native events and traditional healing (Goins, Spencer, McGuire, Goldberg, Wen, & Henderson, 2010). Another study of caregiving of American Indian elders indicated that there were low rates of caregiver burden and high reported rewards (Jarvis, Boland, & Fickenscher, 2010). The researchers found that even in communities with high poverty and alcohol use disorders, there were strong indicators of cultural influence on caregiving relationships. Unique to the culture was a pattern of providing collective care within extended family systems, a complex exchange of assistance (versus a unidirectional provision of care unto the care recipient), an opposition to nursing home placement, lack of competing priorities and a strong sense of reciprocity to keep the elderly care recipient close to the family (Jarvis, Boland, & Fickenscher, 2010). Indeed, further research is warranted in this area, given the differences in self-reported appraisal among American Indians and other less represented minority groups.

VI. Perceived Benefits of Caregiving

Hogsted, Curry, and Walker (2006) provided an alternative view of the benefits of informal family caregiving with a study of a workplace caregiver support group who were mostly Caucasian women. Themes which emerged from personal accounts of caregivers included four main categories: celebrating the small things, resolving past hurts and conflicts, developing personal strength and aging readiness, and experiencing the older person's full life (here and now, there and then) (Hogsted, Curry, & Walker, 2006, p. 59). The phenomenon of "benefit finding" was explored in adult children caregivers of patients with cancer and was shown to be positively associated with emotional satisfaction with caregiving experiences (Levesque & Mayberry, 2014). In a study of caregivers of heart failure patients it was found that relationship quality was positively associated with caregiver benefit and negatively associated with both caregiver burden and depression (Lum, Lo, Hooker, & Bekelman, 2014). A study of husbands of breast cancer patients reported that there were reported benefits of caregiving during active cancer treatment of their wives, but there was also a domestic role strain component which added to psychological stress in some of the sample (Wagner, Tanmoy Das, Bigatti, & Storniolo, 2011).

A. Caregiving in Various Settings

It is important to note that family caregiving continues past the immediate physical care environment and may follow a care recipient's admission to a nursing home or special care unit. Reasons for nursing home placement have been studied and were associated

with caregiver burden and reaction to behavior problems, caregiver health, quality of the relationship, and either being employed with demands of time or being unemployed with financial strain (Brodaty, McGilchrist, Harris, & Peters, 1993). Butcher, Holkup, Park, and Maas (2001) explored the experience of caregivers who were deciding to place a family member with Alzheimer's disease in a special care unit. There were four main themes which emerged which identified a potentially stressful situation where a decision was to be made and then acted upon. Family members reported "moving toward the unavoidable decision, struggling with the decision, seeking reassurance, and finding ways to stay connected after the placement of their family member in an institution" (Butcher, Holkup, Park, & Maas, 2001, p. 470). Removing the physical demands of caregiving by placing a care recipient in a nursing home still does not necessarily erase the emotional strain. Major emotional stressors which continue may include anxiety, depression, guilt, anger, and financial strain (Schulz, Belle, & Czaja, 2004).

As was previously stated, 60 percent of family caregivers who care for adult care recipients are employed full or part-time (AARP Public Policy Institute, 2015). Duxbury, Higgins, and Smart (2011) presented findings that work-life balance added another component to many caregiver's experiences. Situational factors which were associated with varying amounts of caregiver strain included location of care provision (living with the recipient, within the same community, or at a distance), gender, and family type. Regardless of location, the most physical and emotional caregiver strain was reported by women. Employed caregivers, with the recipient residing in the home, showed comparable levels of reported

emotional strain as those caregivers who provided care to someone in the community but not at their home. Caregivers who lived in another community often reported more financial and work related challenges, possibly from the logistical challenges of arranging time off and travel costs (Duxbury, Higgins, & Smart, 2011). Family caregivers have been categorized as eldercare only or a sandwich family (where both child and elderly care were provided). Caregivers who only provided care to elders reported higher appraised caregiver strain. This may be explained by the age of the informal caregiver or having more available caregivers in a sandwich family situation (Duxbury, Higgins, & Smart, 2011).

VII. Caregiver Assessment Measures

Over the last decade there has been a paradigm shift in some social service and health service agencies, including Area Agencies on Aging (Dickol, 2009). The old paradigm was to refer caregivers to case management based on the needs of the care recipient, often neglecting the potential needs of the caregiver. Often the services were funding-centered, short term, and potentially fragmented with the thought that helping the care recipient would ease potential caregiver strain (Dickol, 2009). More recently, however, demonstration projects have shown that immediate screening upon admission to a case management team should include measures of caregiver strain which then can inform the development of an individualized plan of care (Dickol, 2009). This clearly is a more family-centered approach and opens the path for continued surveillance of potential caregiver strain as care needs change and evolve.

The Caregiver Family Alliance (2012) compiled a resource inventory of caregiver

assessment measures for health care practitioners who work with families and informal caregivers. The measures are organized according to seven conceptual domains representing a range of issues faced by informal caregivers. Those interested in exploring these practice oriented instruments may find them in the 2nd Edition of [Selected Caregiver Assessment Measures](#). The seven conceptual domains, with related constructs, are listed below (Table 2). Information about each measure selected for inclusion in the compendium includes: a) the measure name, b) author and year of published sources, c) number of items, d) response options, e) reliability and validity, and f) a description of the construct/s it measures and sample questions if available.

Table 2: Conceptual Domains for Caregiver Assessment Measures

Conceptual Domains	Individual Constructs
Context of caregiving	<ul style="list-style-type: none"> • Caregiver relationship to care recipient • Physical environments • Household status • Financial status • Quality of family relationships • Duration of caregiving • Employment status • General demographics
Caregiver’s perceptions of health and functional status of care recipient	<ul style="list-style-type: none"> • Activities of Daily Living • Psycho-social needs • Cognitive impairment • Behavioral problems • Medical tests and procedures • Pain
Caregiver values and preferences	<ul style="list-style-type: none"> • Caregiver/care recipient willingness to assume/accept care • Perceived filial obligations to provide care • Culturally based norms • Preferences for scheduling and delivery of care services
Well-being of the caregiver	<ul style="list-style-type: none"> • Self-rated health • Health conditions and symptoms • Depression or other emotional distress (e.g., anxiety) • Life satisfaction/quality of life
Consequences of caregiving	<ul style="list-style-type: none"> • Perceived challenges <ul style="list-style-type: none"> - Social isolation - Work strain - Emotional health strain - Physical health strain - Grief/loss - Financial strain - Family relationship strain • Perceived Benefits <ul style="list-style-type: none"> - Caregiver satisfaction with helping care recipient - Developing new skills and competencies

Conceptual Domains	Individual Constructs
Skill/abilities/knowledge to provide care recipient with needed care	<ul style="list-style-type: none"> • Caregiving confidence and competencies • Appropriate knowledge of medical care tasks (wound care, etc.)
Potential resources that caregiver could choose to use	<ul style="list-style-type: none"> • Use and perceived quality of formal and informal helping • Perceived quality of emotional support • Existing or potential strengths • Coping strategies • Financial resources (health care service benefits, entitlements such as VA, Medicare) • Nursing home support

From: Schwarts, S., Darlak, L., & Whitlatch, C. (2013). *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners* (2nd ed.). Family Caregiver Alliance and Benjamin Rose Institute on Aging. Retrieved from: http://www.caregiver.org?isp?content/pdfs/op_2002_resource_inventory.pdf.

VIII. Assessing Caregiving in the Community and Across Health Care Settings

Given the high prevalence of family and informal caregiving coupled with an aging society, it is imperative that health care providers and social service staff be proficient and comfortable with speaking about family caregiving experiences. The studies of mortality rates associated with caregiving experiences should be enough of an indication that both emotional and physical strain of caregiving is costing lives, quality of life, and health care dollars. The sheer numbers of family caregivers who provide significant hours of care every week is an indication of a pervasive and growing health care need. As the U.S. health care system is re-structuring, it is asserted that new models of health care could put more emphasis on recognizing the invisible and invaluable aspects of caregiving. Screening of potential caregiver strain should be incorporated within transitional care, primary care, long-

term care, home care, and community settings. Assessing caregiving strain over time as the disease trajectory unfolds is central to this assessment (Onega, 2008).

A. Screening for Caregiver Strain

Upon review of available screening tools for the assessment of caregiver strain, the Modified Caregiver Strain Index (MCSI) was selected as an appropriate instrument for use in the Geriatric Health Screening program and other settings. This instrument can be found under the Consequences Domain: Perceived Challenges: Emotional Health Strain in the *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners* compendium (Schwartz, Darlak, & Whitlatch, 2013).

The Modified Caregiver Strain Index (MCSI) was selected as a screening tool was selected for the following reasons:

- a. It is general in scope, with at least one item of its 13 questions for each of the following major caregiving domains: financial, physical, psychological, and social/personal.
- b. Its psychometric properties are robust—see discussion below.
- c. It is a brief instrument and easily administered either by the caregiver him/herself or via health care professional interview.
- d. The results are useful for identifying areas needing more in-depth assessment and interventions in an effort to alleviate current strain and avert further complications.

- e. It has been listed in the best practices “*Try This*” series provided by the Hartford Institute of Geriatric Nursing (Onega, 2013). See Appendix A.
- f. It has an accompanying instructional video to assist in the practical administration of the tool in community and clinical settings. The video is described in more detail later in the module and will be viewed as part of the requirements for module completion.
- g. Both the tool and the video are available in the public domain at the following websites: Modified Caregiver Strain Index (MCSI) tool and Accompanying Video <https://consultgeri.org/try-this/general-assessment/issue-14>

B. Development of the MCSI

This tool was modified from the original Caregiver Strain Index (CSI) which was first developed and validated by Robinson (1983). The original tool included 13 questions which were intended to measure strain with care provisions. The tool required a dichotomous “yes” or “no” response to questions surrounding employment, financial, physical, social and time domains (Sullivan, 2002). A score of seven or more “yes” answers was determined to be indicative of strain. Internal consistency reliability was high ($\alpha=0.86$). Validity was correlated with physical and emotional health of the caregiver and self-reports by caregivers of their situation (Sullivan, 2002).

In 2003, Thorton and Travis adapted the original Caregiver Strain Index by refining some items on the tool in response to further inquiry into available research. The result was the creation of the Modified Caregiver Strain Index (MCSI). Four main domains emerged which included the financial, physical, psychological, and personal/social areas of potential

caregiver strain. The modified tool still contains 13 questions and measures four domains. However, because some respondents to the original version had expressed uneasiness with having to choose from a “yes” or “no” dichotomous scale, a third, “yes, sometimes,” option has been added (Thorton & Travis, 2003). The scoring of the responses is 2 for every “yes” answer, 1 for “yes, sometimes” answers and 0 for “no” answers for a total of 26 potential points for the highest possible caregiver strain (Thorton & Travis, 2003). There is no cut-off score to indicate higher levels of strain.

Psychometric Testing of the MCSI

The internal reliability coefficient of the MCSI was slightly higher ($\alpha=0.9$) than that of the original CSI. In the test-retest analysis the reliability coefficient was 0.88 (Sullivan, 2008). With their developmental work on the MCSI, Thorton and Travis (2003) also utilized the Family Caregiver Medication Hassles Scale developed by Travis, Bethea, and Winn (2006) in order to test validity of the new version of the tool. The 24 item medication “hassles” tool was conceptually based on the idea that minor irritations with implementing a medication regimen by the caregiver could build up over time and contribute to caregiver strain (Thorton & Travis, 2003). The Family Caregiver Medication Hassles Scale was significantly correlated with the MCSI ($r=0.44$, $p=0.001$) (Thorton, & Travis, 2003). Additional data on caregiver circumstances and characteristics from well-defined measures were correlated with the newly developed MSCI. The care recipient’s mental status and physical functioning were significantly correlated ($r=0.34$, $r=0.27$, respectively) and when these were combined into a

Statistical Terms

Reliability: The consistency and dependability of an instrument to measure a variable

Internal consistency reliability: The degree to which the various items in an instrument measure the same construct.

Test-retest reliability: An estimate of reliability of an instrument determined by comparing results of testing at two different times with the same group of people.

Validity: The degree to which an instrument measures what it is supposed to measure.

From: Doordan, A.M. (1998). *Research Survival Guide*. Philadelphia: Lippincott.

global functioning measure they were correlated ($r=0.32$) and significant at $p<0.0001$ (Onega, 2008). When the MCSI was correlated with caregiver age and the amount of time the caregiver had been providing care, the younger, long-term caregivers had significantly higher levels of strain ($p=0.00$). When correlated with age of care recipient, the older the care recipient, the more strain was reported by caregivers ($p=0.03$) (Thorton & Travis, 2003).

C. Using the MCSI

General Use

The Modified Care Strain Index was designed to provide a baseline at the beginning of a care episode, measure long-standing strain in long-term caregiving, and provide intermittent measures of strain over time. Onega (2008) noted that screening should not be limited to primary caregivers, but should be considered for screening other family caregivers, friends, and neighbors, even if the care is provided on an intermittent basis. It is considered to be a fast and portable tool which can be utilized in primary care clinics, acute care (while planning discharge needs), home care, community health centers, and sub-acute settings such as assisted living and long-term care facilities (Onega, 2008).

Use in the Community Settings: Specifically IPHARM

One goal for completing this module is to develop skill and confidence in assessing caregiver strain in community settings. For the purposes of this module, a process suggested by the Montana Geriatric Workforce Enhancement Program (MGWEP) is presented for use. The *ImProving Health Among Rural Montanans* (IPHARM) project has been conducting health

screenings within this program on a state-wide basis for over a decade. The geriatric screening arm of the MGWEP grant has provided this module for use as a caregiver strain screening tool, specifically the MCSI, in a community setting.

The screening will be administered by an interdisciplinary student team associated with the IPHARM program, which is administered by the Montana Geriatric Workforce Enhancement Program. It will be advertised as “Caregiver Screening”. As clients arrive at the IPHARM screening site, they will be asked two questions:

1. “Are you currently providing care on an ongoing basis to a family member, friend, or neighbor with a chronic illness or disability?”
2. If yes, “Would you be interested in participating in a short screening which may indicate if caregiving may or may not be a strain on your health?”

The first question mirrors the question posed by Perkin, Howard, and Wadley (2013) in the REGARDS study. The researchers’ follow-up question was intended to ask if this caregiving situation was causing “no strain”, “some strain” or “a lot of strain.” Instead of this question, a short quantitative screening tool is proposed.

D. Administering the MCSI

It is recommended that before administering the screening tool the caregiver is given an explanation such as “a family member’s chronic illness is difficult for both the patient and family members” (Onega, 2008, p. 64). The MCSI may be administered either by paper and pencil with

the client responding to the questions on his or her own, or the questions and examples may be read aloud by an appropriate health professional that then can mark the response. An example is the item “My sleep is disturbed.” The explanation provided under this item is “The person I care for is in and out of bed or wanders around at night.” The caregiver has the option to indicate “Yes, on a regular basis (2 points), “Yes, Sometimes (1 point), or “No” (0 points) either verbally or by writing the response on paper.

E. Scoring of the MCSI

There is a total of 13 items in the index with the highest possible score being 26 points. The index is designed to provide a quantitative score of individual caregiver appraised strain. Much like a pain scale, it is used to indicate a rating which can change over time and is to be considered what the caregiver reports. In practical terms pain is what the client says it is and strain is what the caregiver says it is.

For example, if the index was administered twice in a 3 month interval, and the score rose from 8 to 12, the reason for the increased strain could be explained by those items showing an increase. In a scenario in which a caregiver indicates “there have been work adjustments” and also “caregiving is a financial strain,” and these scores increased since the last MCSI was administered, it gives the clinician a quick indication of what might be happening with the caregiver in terms of appraised strain.

F. Discussing the results

Onega (2008) provided a clear example of how a clinician should discuss the results using an open-ended interview strategy. The clinician could 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 your?” In this way, the conversation moves to problem solving.” (Onega, 2008, p. 68).

The following video illustrates an assessment of caregiver strain provided by the Hartford Institute for Geriatric Nursing. The video provides clear information on how to discuss results with caregivers. Watching the video is a component of the contact hours for this module and should be completed at this time. [View the Modified Caregiver Strain Index video](#) it is 29 minutes long.

Upon review of the video it is expected that the health care provider will be more comfortable in implementing the MCSI with an actual client in a clinical situation or a health screening by modeling the approach taken by the facilitator. It is emphasized in the video that administration of the screening tool does not yield a diagnosis of caregiver strain but that it is very helpful in gauging which areas are of most concern to a particular caregiver. The four domains of caregiver strain are discussed including physical, psychological, financial, and personal/social considerations. An inter-disciplinary care-conference follows the screening procedure and shows how a team approach can assist caregivers by focusing on the perceived experience of the caregiver within a variety of settings. Additional caregiver resources are

provided along with suggestions for individualized care strategies with a person who reports caregiver strain. It is also suggested in the video that other screening tools may be appropriate to use in conjunction with the MCSI such as the Geriatric Depression Scale which is provided in another IPHARM health screening module. See the MTGEC module, *Screening for Depression*, for more information.

G. Challenges to Using the MCSI

The tool does not take long to administer and is a one page portable assessment that can be shared with a primary provider, or any interdisciplinary healthcare team member. It is intended to be a proactive assessment tool in order to focus on prevention by gaining insight into the 13 constructs that support the measurement of caregiver role strain (Onega, 2008). Although the MCSI does not take long to administer, time is limited in a medical office, pharmacy, community clinic, or various other settings to allow for the provision of needed interventions, including information, referral and follow-up. The index can also be used to emphasize primary prevention by assessing the actual issues which may potentially cause strain for a caregiver at a given point in time. Onega (2008) recognized the one challenge to using the index is that it takes more time and effort without tangible reimbursement in a traditional health care system. As new health care models emerge, the utility of health promoting evidence- based tools may become more highly regarded.

H. Follow-up Referral

In the event a follow-up referral is indicated, the clinician (or faculty supervised IPHARM health professions student) may utilize the resources provided in the following tables. The information provided in Table 3 lists Area Agencies on Aging in Montana, the contact information, and the counties and reservations which are served through the various offices and locations. The screening participant can be assisted by providing a fresh copy of the MCSI tool for use at some future point in time and to share with their health care provider if they so choose. Additionally, the resources presented below may assist IPHARM students and supervising faculty to help the participant in their local areas or counties by providing information and appropriate referrals at the caregiver's request.

Table 3: Area Agencies on Aging

Area Agency on Aging	Contact Information	Counties & Reservations Served	
Area I	Action for Eastern Montana 2030 N Merrill Avenue PO Box 1309 Glendive, MT 59330-1309 406-377-3564 FAX 406-377-3570	Carter Custer Daniels Dawson Fallon Fort Peck Garfield McCone Phillips	Powder River Prairie Richland Roosevelt Rosebud Sheridan Treasure Valley Wibaux
Area II	PO Box 127 1502 4 th Street West Roundup, MT 59072-0127 406-323-1320 FAX 406-323-3859	Big Horn Crow Carbon Fergus Golden Valley Judith Basin Musselshell	Northern Cheyenne Petroleum Stillwater Sweet Grass Wheatland Yellowstone
Area III	North Central Area III 311 South Virginia St., Ste. 2 Conrad, MT 59425-2358 406-271-7553 FAX 406-271-2769	Blaine Blackfeet Chouteau Fort Belknap Glacier	Liberty Pondera Teton Toole
Area IV	PO Box 1717 648 Jackson St. Helena, MT 59624-2358 406-447-1680 FAX 406-447-1329	Broadwater Gallatin Jefferson	Lewis & Clark Meagher Park
Area V	Southwest Montana Aging and Disability Services PO Box 459 1015 South Montana Street Butte, MT 59703 406-782-5555 FAX 406-782-5662	Beaverhead Deer Lodge Granite	Madison Powell Silver Bow
Area VI	Western Montana Area VI Agency on Aging, Inc. 110 Main Street, Ste. 5 Polson, MT 59860-2127 406-883-7284 FAX 406-883-7363	Lake Lincoln Mineral	Salish-Kootenai Sanders

Area Agency on Aging	Contact Information	Counties & Reservations Served	
Area VII	Missoula Aging Services 337 Stephens Missoula, MT 59801-4301 406-728-7682 FAX 406-728-7687	Missoula Ravalli	
Area VIII	Cascade County Aging Services 1801 Benefis Court Great Falls, MT 59405 406-454-6990 FAX 406-454-6991	Cascade	
Area IX	160 Kelly Kalispell, MT 59901-5143 406-758-5730 FAX 406-758-5732	Flathead	
Area X	Hill County Council on Aging 2 West Second Street Havre, MT 59501-3434 406-265-5464 FAX 406-265-3611	Hill Rocky Boy	

From: Montana Department of Public Health and Human Services: Senior & Long Term Care Division—Office on Aging. (no date). Montana Aging Services Network. Map accessed (2016): <https://dphhs.mt.gov/Portals/85/sltc/documents/AAA/AAAmap.pdf>

Table 4 provides the websites and description of state-wide aging services in Montana.

Table 4: Websites: Statewide Aging Services

Service Title/Website	Description
<p>Montana Department of Health and Human Services (MT DPHHS)</p> <p>Website: http://dphhs.mt.gov/</p>	<p>Click on the Seniors tab at the top of the page. This will take you to a list of 24 categories of services for seniors. Click on the titles, and it will link you to a list of services, with location and contact information, across the state.</p> <p>Below are selected examples of the resources found connected to the categories:</p> <ul style="list-style-type: none"> • http://www.montana-adrc.com/ (ADRC directory) • http://dphhs.mt.gov/SLTC/csb (Home and Community Based Services) • http://dphhs.mt.gov/SLTC/aging/adrc/information (Information and Referral Services) • http://dphhs.mt.gov/respice (Life Span Respite) • http://dphhs.mt.gov/SLTC/aging/adrc/optionscounseling (Options Counseling)
<p>Area Agencies on Aging</p> <p>http://dphhs.mt.gov/sltc/aging/areaagenciesonaging.aspx</p>	<p>The Area Agencies on Aging (AAA) are private non- profit or public agencies. On this website you can find links to those AAAs that have websites, Montana Senior Centers, and Human Resources Development Council.</p>
<p>Montana State Unit on Aging (Senior and Long Term Care Division of the MT DPHHS).</p>	<p>Montana State unit on aging administers a variety of aging services, which may be found at this website. These include:</p> <ul style="list-style-type: none"> • Aging Horizons • What's New in Aging • Area Agencies on Aging • Montana's Older American Act • Long Term Care Insurance • SHIP • Long Term Care Ombudsman • Legal Services Developer Program • Nutrition • Montana Senior Medicare Patrol (SMP)

Additionally APPENDIX B provides a list of web-sites at the national level which may be helpful to both the participant who reports strain and also the health care professional who needs to individualize a plan of care for the caregiver.

IX. Summary

Upon completion of this module it is hoped that members of an interdisciplinary health care team can appreciate the role that informal caregiving plays in our health care system. From a review of the literature it is apparent that the experience of caregiving is a unique lived experience and is situationally and culturally influenced. Often informal caregiving is not recognized in the plan of care and this care can be both invisible and invaluable both individually and across the entire health care system. Using a case example from the video, an evidence-based screening tool (MCSI) is demonstrated in practice along with an interdisciplinary model of planning for future care to assist an elderly client who is experiencing caregiver strain. Multiple resources are provided for both individual caregivers and their families and also for health care providers who are interacting with clients in a variety of care settings.

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The Modified Caregiver Strain Index (MCSI)

By Lisa L. Onega, PhD, RN, Radford University School of Nursing

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, financial hardship, and changes in social relationships. They may also experience physical health problems (Thornton & Travis, 2003). Perceived caregiver strain has been associated with premature institutionalization for care recipients along with 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 (MCSI) 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: Financial, Physical, Psychological, Social, and Personal. This instrument can be used to assess individuals of any age who have assumed the caregiving role for an older adult. The Modified Caregiver Strain Index (MCSI) is a more recent version of the Caregiver Strain Index (CSI) developed in 1983. The MCSI was modified and developed in 2003 with a sample of 158 family caregivers providing assistance to older adults living in a community-based setting. 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 (Travis et al., 2003; Thornton & Travis, 2003).

VALIDITY AND RELIABILITY: The 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 ($n=53$) was available and resulted in a test-retest reliability coefficient of .88 (Thornton & Travis, 2003).

STRENGTHS AND LIMITATIONS: The MCSI is a brief, easy to use, self-administered instrument. Long-term family caregivers were not comfortable with the dichotomous choice on the CSI; the modified instrument provides the ability to choose a middle category response best suited to some situations (Travis et al., 2003). The MCSI 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. Caregiver strain scores are not categorized as low, moderate, or high, 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 MCSI, 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 older adult care recipient'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, financial strain, 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.

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

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The Hartford Institute would like to acknowledge the original author of this Try This® issue: M. Terry Sullivan.



A series provided by The Hartford Institute for Geriatric Nursing, New York University, College of Nursing

EMAIL hartford.ign@nyu.edu HARTFORD INSTITUTE WEBSITE www.hartfordign.org
CLINICAL NURSING WEBSITE www.ConsultGerIRN.org

APPENDIX B: Online Resources for Caregiving

Resource/Website	Comments
<u>AARP Navigating the World of Caregiving</u>	Includes topics such as planning ahead, providing care at home, preparing your home, housing options, legal and insurance issues, and end-of- life issues.
<u>AARP 2015 National Survey of Caregivers of Registered Voters Age 40 and Older</u>	Graphic and brief presentation of the results of the 2015 Survey, with a focus on policy change that will help caregivers.
<u>AARP Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain</u>	A comprehensive report on the current state of caregiving in the United States.
<u>American Cancer Society</u>	Provides information about caregiving and coping.
<u>Alzheimer's Association</u>	The mission of the Alzheimer's Association is to advance research to eliminate Alzheimer's disease, to provide support to all who are affected by it, and to reduce the risk of the disease through brain health.
<u>Alzheimer's Association Caregivers</u>	The Alzheimer's Association recognizes the tremendous toll involved in caregiving. It has multiple resources on many diverse topics for caregivers.
<u>Behavioral Risk Factor Surveillance System (BRFSS)</u>	A primary source of state-based data on health risk behaviors of adults age 18 or older. Demographic data are also collected, so interventions can target people at greatest risk. (This is Montana's website for BRFSS information.) <u>The Montana 2016 Questionnaire includes caregiving questions.</u>
<u>Cancer Care</u>	Provides links to various online cancer caregiver support groups.
<u>Caregiver Action Network</u> (formerly National Family Caregivers Association)	Provides information for a broad array of caregivers across the age and disease spectrum, from caregiving for young children with health challenges to older adults with dementia.

Resource/Website	Comments
Care Pages.com	Offers free patient blogs to facilitate connections among family members and friends with the goal of providing support to a loved one experiencing a health challenge.
Caring Bridge	Similar to Care Pages, this website facilitates the transformation of personal connections into support during a health difficulty.
ConsultGeri: Nursing Standard of Practice Protocol: Family Caregiving	A clinical website of The Hartford Institute for Geriatric Nursing with the mission to ensure that older adults achieve optimal health and quality of life.
Family Caregiving Alliance	Information about multiple aspects of caregiving including preparation for caregiving, being new to caregiving, daily and in-home caregiving, long distance caregiving, caregiving and advanced illness, and post-caregiving.
The John A. Hartford Foundation, Caregiving Resources	Multiple links to caregiving resources under each of the following topics: a) resources for individual caregivers b) finding help and support, c) care transitions, d) respite care, e) dementia caregiving, and f) caregiving for veterans.
The Leukemia and Lymphoma Society	Although this website covers several needed resources for patient/families/friends of people with leukemia and lymphoma, there is a section directly related to caregiving .
The National Alliance for Caregiving	A broad-based organization devoted to family caregiving. Topics include research, advocacy, state and local coalitions, caregiving champions, and resources.
National Cancer Institute	One of the research institutes at the National Institutes of Health, this institute provides a robust website about all aspects of cancer. It has an excellent section on resources for caregivers.
National Caregiving Foundation	This site provides detailed information about veterans, suicide, and Alzheimer's/long term care. A free Caregiver's Support Kit can be found here.

Resource/Website	Comments
National Guideline Clearing House	A public resource for evidence-based clinical practice guidelines for health care practitioners.
Rosalyn Carter Institute for Caregiving	<p>The goal of this institute is to support both informal and professional caregivers through advocacy, education, research, and service.</p> <p>A comprehensive compendium of caregiver assessment measures titled, Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners (2nd ed) can be found here.</p>

Appendix C: Post-test Assessment of Caregiver Strain

Record responses on examination form.

1. What percentage of unpaid care provided to older adults is provided by family members?
 - a. 25 %
 - b. 50%
 - c. 60%
 - d. 85%

2. The most accurate definition of *caregiver strain* is?
 - a. An individual's physical and/or emotional response to challenges in the caregiver role.
 - b. The caregiver's perception of enduring problems or an altered state of well-being.
 - c. The burden experienced when a caregiver is providing intensive care (greater than 21 hours a week).
 - d. The physical and psychological outcomes experienced by a caregiver who provides extensive and prolonged care.

3. The pathophysiology of caregiver strain includes
 - a. Autonomic disruptions and changes in the diurnal rhythm of the HPA axis.
 - b. Decreased cortisol levels secreted by the adrenal cortex.
 - c. A shift to high morning and decreased evening cortisol levels.
 - d. A physical response to chronic stress that does not include changes in emotional health.

4. Findings from the Alzheimer's Association (2015) indicated that
 - a. 59% of caregivers reported high or very high emotional stress with caregiving.
 - b. 59% of caregivers reported high or very high physical stress with caregiving.
 - c. The number of hours of caregiving directly affects self-reported caregiver strain.
 - d. In the last year of caregiving 35% of caregivers reported they were "on duty" 24 hours a day.

5. Which of the following characteristics was NOT found to be positively correlated with being a caregiver in American Indian communities?
 - a. Participant in traditional healing events
 - b. Large family size
 - c. Younger female
 - d. Socio-economic status

6. Self-reported benefits of informal family caregiving have included all listed EXCEPT
 - a. Developing personal strength and aging readiness
 - b. Resolving past hurts and conflicts
 - c. Experiencing the older person's full life (here and now and there and then)
 - d. Preserving financial resources for providing care themselves

7. Which statement is INCONSISTENT with the Healthy Caregiver Hypothesis?
 - a. Coping with mild levels of stress has been found to be physiologically and psychologically protective.
 - b. Feelings of self-efficacy and reliance may result from coping with mild levels of stress.
 - c. The intensity and duration of caregiving are main factors in the health of the caregiver.
 - d. There may be time-sensitive health benefits related to a caregiving episode.

8. Which of the following statements is most appropriate for the administration of the MCSI?
 - a. The directions are self-explanatory and there is no need to converse about the need for the screening.
 - b. Since the possible responses are “yes” or “no” to the 13 items this makes scoring simple.
 - c. The MCSI was designed to screen only immediate caregivers.
 - d. The MCSI was designed to be administered at different points in time to monitor continuing effects of caregiving.

9. Appropriate follow-up for caregivers who score high on the MCSI include:
 - e. The care recipient’s cognitive status and behaviors
 - f. The caregiver’s perception of role overload or deprivation in relationships, goals or activities
 - g. The work-role and caregiving conflict
 - h. All of the above

10. When discussing results of the MCSI with caregivers it is recommended that
 - e. Health care professionals start with an open-ended interview strategy
 - f. Health care professionals gradually ask more focused questions leading to “What may make things easier for you?”
 - g. Health care professionals move the discussion to problem solving while discussing the key items on the MCSI where the caregiver reports strain
 - h. All of the above

POST-TEST: Examination Form
Assessment of Caregiver Strain

Participant Information

- 1. Name: _____
- 2. Mailing address: _____

- 3. Date exam completed _____

Questions: (Please circle one response per question)

1	A	B	C	D
2	A	B	C	D
3	A	B	C	D
4	A	B	C	D
5	A	B	C	D
6	A	B	C	D
7	A	B	C	D
8	A	B	C	D
9	A	B	C	D
10	A	B	C	D

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Appendix D: Evaluation: Assessment of Caregiver Strain

Please indicate your major									
				Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Don't Know
1. Based on the module description and stated objectives, this module met my expectations of the content it would deliver.				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How effective were the following in helping you understand the material?				Very Effective	Effective	Neutral	Somewhat Effective	Not Effective	Not Applicable
Pre-test				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Written Text				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Videos/Photos				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Websites/Web Links				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
References				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Case Studies				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Don't Know
3. I learned something I can use in my practice/employment or personal setting.				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				Provide new information to patients/clients	Adjust practices with geriatric patients/clients	New program development or program enhancement	Provide new information to family/friends/ co-workers	Train staff or provider	Other implementation*
4. How do you plan to implement the information from this module to strengthen your practice, employment or personal goals? (check any that apply)				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				* Describe 'other' implementation plan here:					

				<1 hour	1-2 hours	2-3 hours	3-4 hours	4-5 hours	>5 hours
5. How long did it take you to complete the module? (including pre-test, module review, post-test and evaluation)				0	0	0	0	0	0
				Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't Know
6. The test questions were relevant to the module content.									
7. Please provide suggestions to improve the online learning experience to meet your needs.									
8. Please offer ideas or suggestions for new modules.									

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