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THE FIFTH PATIENT HISTORY QUESTION: Are You A Care Giver?

Clinicians routinely ask social history questions that involve; smoking, alcohol, diet, and exercise. The fifth question should be; “Are you a caregiver?”

Background: Our aging society leaves many adults in the caregiving “sandwich” of parenting children while caring for aging parents. We educate and prepare expectant parents but we have no similar system for preparing adults to become senior caregivers. Many studies have documented stress as a contributing factor to poor health. AARP, Alzheimer Association and ASA offer research and tips on their websites for caregivers (1) (2) and (3).

Demographic comparison: In 1910, the average life span was 50.23 years for white males and 53.62 for white females (4); in 2010, it was 78.5 years average for both sexes (5). In 1910, less than 7% of the population, an estimated 6,280 people over 60 lived in Sangamon County, Illinois (6) (7). In 2010, that rose to 19.9% or 39,204 seniors in Sangamon County (8)! The community impact of caregiving results from the *numbers of seniors* as well as their longer lifespans. The chance that your patient is providing some form of senior caregiving becomes inevitable.

We have borne children for millennia. We have had a significant elder population for *less than a century*. That explains why senior care data is much less than childcare data. While the medical community has successfully educated society about the dangers of smoking, we do not *systematically educate* families about senior caregiving or managing its potential negative medical outcomes for caregivers. Illinois was one of the states sampled in the Alzheimer Organization-funded study titled, *Caregiving in the United States [BRFSS]*. 72.8% of dementia patient caregivers were married, and 63.1% of non-dementia patient caregivers were married. 34.1% of dementia caregivers a child still living at home: 34.1% and 41.5% for non-dementia caregivers (9). Demands of caregiving can also cause marital conflicts that create additional stress on the caregiver.

Caregiver Profile: According to the Alzheimer Association, 66% of the caregivers are women (10). *The last two censuses found that women spend more years caring for a senior than they spend rearing her children* (11). Most women enter the peak senior caregiving phase around age 35. However, according to the BRFSS survey, 43.9% are still caregiving at age 85+ (12). Illinois has 210,000 persons diagnosed with some form of dementia (12). The Alzheimer Association estimates caregivers provided 17.5 million hours of unpaid care in 2011 (13). Caregivers sometimes give up jobs, promotions, or career advancements in order to provide care (14). Because these demographic phenomena are so extensive, clinicians would benefit knowing whether senior caregiving is part of the patient’s social history.

5th question caution: Adult children usually do not self-identify as caregivers. The clinician needs to derive a caregiving profile by asking a follow up questions, *even if the patient answers “No”*. These questions serve to educate patients about all the forms of caregiving. The clinical identifiers look the same as other stress reactions. Caregiving questions help identify this source of social history stress in order to promote discussion to prevent burnout.

HELPING THE PATIENT IMPROVE OUTCOMES

First: Know the myths. Many caregivers perceive that, if they are not bathing and feeding someone, they are not caregiving. Caregiving actually begins with less personal forms: yard work, financial tasks, shopping, and accompanying the elder to medical appointments. Only later do more hands-on forms of caregiving enter the process.

Second: Remember, caregivers may not realize how much time and effort they spend. Often, it is only when someone else (spouse, child, or boss) complains of lack of attention that the caregiver recognizes *the effect on others* but not necessarily on themselves. At that point, your patient may be ready to examine how much time and effort they actually invest.

Third: Look for the presentations. Many caregivers will try to do it all without help. Signs of overwork present *emotionally and physically*. *Only when some symptom has forced them to re-assess their situation do they realize how much caregiving takes. That symptom propels them into your office and creates a *teachable moment*.* The fifth social history question raises patient awareness to the causes for their symptoms. Long-term stressors, such as caregiving, likely contribute to symptoms and illnesses.

Fourth: Raise patient awareness to bring greater cooperation in addressing lifestyle issues. Once the caregiver connects negative symptoms to the caregiving role, they will be more receptive to support groups, classes, or asking family members to take some responsibility. When they understand the importance, patients willingly provide more social history details. The clinician may find other options to address the stress-symptoms connection.

Fifth: *Warn the patient against allowing caregiving to distract them from their own health care.* I have seen adult children who ignored their own deteriorating health because the senior “needed” them. In one case, it led to early death, in another it led to attempted suicide. We are familiar with the usual barriers to healthcare: no insurance, lack of transportation, lack of community resources, or poor education. I suggest that the *distraction of caregiving is another barrier to healthcare.*

Etiology: The constancy of care erodes the mental and physical health of the caregiver. Like the river that created the Grand Canyon, caregiving never stops; it just changes form. When caregivers are not *doing the care* they are *thinking about care*. Caregivers are *planning the other parts of their lives around caregiving* or they are *worrying about* the care recipient. This last issue is especially true when the loved ones do not live nearby. The Alzheimer Association estimates that 15% of caregivers live more than an hour from the loved ones (15).

How many times have you wished your patient had seen you earlier when conditions were more treatable? Caregiving might be a reason they delayed. Adult children use their sick days from work to take *others* to medical care, *not themselves*. The first form of caregiver’s medical care to erode is *preventive*. Helping your patients identify as caregivers allows the clinician to teach them that caring for *themselves enables* them to care for others. The airlines put it best: “Put Your Own Oxygen Mask on First”.

Caregivers may be spouses. ASA's National Family Caregiver Support Program puts the average age for caregivers at 63 years, and 17%-35% of those report their health as poor (16). When the caregiver is a spouse or life partner, all of the above issues apply, and several more. Often the caregiving spouse is often the same age as the recipient, and may have chronic health issues of her own. The spouse may feel that caregiving is part of or her marital role. Couples, who relied on each other for decades, may not believe they need help because they did not before. Parents often cling to the last vestiges of their role by putting off "bothering the children". The couple may worry about a losing independence if they seek help; a move to a nursing home, or separation (one spouse in a facility). The couple may have lost friends through death or moves to retirement-friendly climates; furthering their loss of social support. When the care recipient loses mobility, it further isolates both caregiver and recipient. More pressures on the caregiving spouse lead to adverse health outcomes.

Conclusion: Clinician awareness about the impact of caregiving on health outcomes should result in adding this question to social history screenings. This question demonstrates *the value the clinician places on this issue* and raises awareness of healthcare impacts in patients. Adding this question sensitizes patients to review their situations in light of this factor. A clinician's emphasis on preventive care as well as adherence with caregivers can help turn the tide of caregiver's undiagnosed and untreated conditions. November is National Family Caregivers' Support Month as set forth by the Family Caregiver Act in 1994, and promoted by the American Society on Aging.

Recommendation: That all clinicians include this question, starting November 2013. I further recommend clinicians should post a sign in all waiting rooms to draw attention to *and promote discussion* of the impact of caregiving on health. The sign should read: "Put Your Own Oxygen Mask On First: November is National Caregiver's Month".

FOOT NOTES

1. AARP, (American Association of Retired Persons) www.aarp.org/home-family/caregiving WEB. March 31, 2013; [page; Care for the Caregiver, 15 articles, videos, & 7 resources]
2. Alzheimers Association, [www.alz.org/caregiving tips](http://www.alz.org/caregiving_tips) WEB. March 2013Page: Caregivers
3. ASA (American Society on Aging). WEB. [www.asaging/education/2/node 1459](http://www.asaging/education/2/node_1459). Page; *Caregiving*. [family caregiver support series web Seminars on a rotating date basis]
4. WEB. March, 2013: www.infoplease.com/ipa/A0005150.html Table: "Life Expectancy by Age 1850-2004 [1909-11 for white males and 53.62 for white females]
5. Centers for Disease Control and Prevention [heading; Life Expectancy, Data for US & are final for 2009 data; PDF 724. For the most preliminary data; see Deaths: preliminary data for 2010 KB] WEB, 2013; www.cdc.gov/nchs/faststatslifeexpect.htm
6. *14th Census of the US, Vol. I, Pub 1920, Number and Distribution of Inhabitants, Detailed Tables, # 49; Population by Counties Incorporated Places and Minor Divisions, Page 102.* [Population for 1910; Ill. 5,638,501; Sangamon 91,204]

7. 16th Census of the United States Population, Vol. II, Characteristics, Part 2 Florida – Iowa, Pub.1943, Page 483, Table 8, Illinois, title: Age, Sex by State 1870-1940 [figures derived by adding %s for cohorts 60-75+, including not reported# =6.9% . Therefore, 6.9% of 91,024 for Sangamon County in 1910 = 6,280.656]
8. US Census Bureau, American Fact Finder, Profile of General Population and Housing Characteristics 2010, Sangamon County, Illinois. Total Population by Sex and Age; [figures derived from following info: adding cohorts 60-85+ years=39, 204.] [Figures derived by adding cohort % 60-85+ = 19.9%]
9. Anderson, Elena & Bouldin, Erin. Caregiving in the United States; Behavioral Risk Factor Surveillance System (BRFSS), Pub. 2009, Office on Disability and Health, University of Florida, Page 13, Table 3: WEB. June 2013: www.alz.org/documents_custom/public-health/brfss_caregiver_report.pdf
10. N. Auth. Family Caregiver Alliance of the National Center on Caregiving; Selected Statistics Fact Sheet, WEB. June 2013. www.caregiver.org/caregiver/jsp/content_node.jsp?noeid-439 [Gender: 66% are women]
11. WEB. June 2013; www.Factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml
12. Ibid. BRFSS, table 3, page 13 [ages 35-44 are peak caregiving years if viewed by cohort #s of caregivers. Next highest 45-54 & 55-64] [Page 10, Table 2, caregivers over 85 =43.9%]
13. Alzheimer Association, Page: *Facts and Figures*. WEB. April, 2013 www.alz.org/alzheimers_disease_facts_and_figures.asp#impact [2012, 15.4 million caregivers provided 17.5 million hours of unpaid care valued @ \$216.4 billion]
14. N. Auth. *Journal of Alzheimers and Dementia*, Vol.6, Issue 2, Pub. March 2010, Pages 158-194, Section 5 Caregiving, Subsection 5.2.3.10 Family Caregiving WEB. June 2013 [www.alzheimersanddementia.com/article/51552-5260\(10\)00014-2/fulltext](http://www.alzheimersanddementia.com/article/51552-5260(10)00014-2/fulltext) [”...negative impact on employment, income and financial security...”]
15. Ibid. WEB. June 2013. www.alz.org, *Facts and Figures* [15% live an hour or more from loved ones] [60% rated emotional stress as high or very high] [\$9.1 billion additional health care costs for caregivers’ own health].
16. N. Auth. Family Caregiver Alliance of the National Center on Caregiving; Selected Statistics Fact Sheet; WEB. www.caregiver.org/caregiver/jsp/content_node.jsp?noeid-439 June 2013 [Section: Impact on physical Health, 17% health is worse & 17-35% poor health]