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Assisted Living Column

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Caring for caregivers

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It's been said that the number one factor in one's life that dictates whether you will end up a resident in a nursing home is the number of daughters you have. This is based on the support provided by ones' daughters in their role as the most supportive caregivers, dedicated to keep a loved one safe in the community. Given healthcare provider's new accountability in a value-based world on improving clinical and financial outcomes, supporting caregivers is increasingly being viewed as a requirement for success. As a result, programs that support caregivers are being developed for their major impact on the outcomes for older adults. Beyond is an overview of the 'why' caregivers are so critical; the 'what' caregivers impact is, both positive and negative; and the 'who' and 'how to improve caregiver outcomes.

Why and what caregiver impact

The impact of caregivers on the health of older adults and their use of resources is critical in their role as patient navigator, coordinator, and provider. In the United States, 43.5 million adult family caregivers provide care for someone who is at least 50 years of age while 14.9 million care for someone who has cognitive and functional impairment due to some form of dementia.[8] Often, family members will provide care for parents and in-laws by helping with a variety of important tasks such as grocery shopping, housekeeping, and meal preparation. There are also responsibilities that involve critical aspects of medical well-being such as assistance with taking medications on time. There are the more stressful tasks such as toileting, showering, feeding, and making sure that personal hygiene remains in order. Often, taking on this unpaid responsibility comes with an understanding that one will continue to work their regular job or cut their work hours partially or altogether in order to meet the needs of caring for their loved one, which can take 20 or more hours per week. Keep in mind that caregivers often assume this very difficult responsibility with little or no training or hands-on experience. Just as important and perhaps of higher importance is that there is no training on how to manage the highly stressful change to the caregivers life that is sure to follow.

Caregivers health

An effective caregiver starts with one who is knowledgeable and healthy themselves. There is a great deal of assistance that can be provided here to assure that caregivers have the resources needed for themselves to be healthy as well as knowledgeable about how best to manage the care for their loved ones. This starts with identification of the principle caregiver and interacting with them at each patient encounter. The Family Caregiver Alliance is an organization dedicated to improving the quality of life for caregivers and those they care for through information, services, and advocacy.[1]

Beyond education, caregiver's own health is critical. While researchers have long known that caregiving can have harmful

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mental health effects for caregivers, research also shows that caregiving can have serious physical health consequences. Further supporting this is the fact that 17% of caregivers feel their health in general has gotten worse as a result of their caregiving responsibilities.[2]

This negative impact on caregiver health worsens over time. This steady decline is the result of not only the cumulative effect of burnout but also by the fact that the caregiving needs typically increase over time while at the same time the caregivers own health declines. With both an increasing need and decreasing ability, burnout and declining health of the caregiver is common. Caregivers reporting fair or poor health increases from 14% within first year to 20% after 5 years or more of providing care. Those caring for a spouse are most likely to report fair or poor health (27% versus 15% for all other relationships).[3]

A large number of family caregivers report that caregiving has caused their physical health to deteriorate, this effect is proportional to the number of activities of daily living (ADLs) caregivers perform. Only 16% of caregivers who do not perform ADLs reported detrimental effects on health, versus 20% of those performing 1–2 ADLs, 28% of those performing 3–5 ADLs, and 41% of those performing 6 or more ADLs.[4]

Caregivers who work full-time say they suffer from poorer physical health than their non-caregiving counterparts. And the stress of caregiving continues even after the job is done. Caregivers who provide care for persons with dementia risk compromising their immune systems for up to 3 years after their caregiving experience ends thus increasing their chances of developing a chronic illness themselves.[4] For all these reasons, caring for caregivers to reduce this stress is critical in assuring that caregivers can be supportive in a positive manner and prevent negative issues from arising such as elder abuse.

Keys to caregiver health

The first thing you should think about prior to taking on the responsibility of providing care for another person is your own health status. How strong is your physical and emotional foundation, and how will you respond to this change in your life? Think about the physical requirements that are needed to help another person and ask your doctor if they feel you will be able to handle the load. Assess your nutritional state and your eating habits and develop strategies to help you maintain or improve those.

Do not underestimate the importance of exercise. Exercise helps to elevate mood and reduce stress while promoting better sleeping habits. The end result is that you will have more energy and hold a better outlook. Many of us avoid doing exercise because we think it will take too much time or that we don't have the equipment we need to do an effective workout. Neither of these points are true. Walking is an easy and effective way to start your workout routine. Try starting with three walks of twenty minutes per week. If time does not allow you to take 20-min blocks of time to walk, start by walking for as long as you can and if you cannot do it consistently 3 times a week, do it as many days a week as you are able to do.

As you work on improving your physical condition, do not neglect your emotional health. As you go through the difficulties in caring for a frail and vulnerable loved one there will be many occasions where her emotions will run high to the point where you will risk having these emotions take control of you. Emotions are important cues for us to pay attention to, but we cannot let them control us if we want to perform the tasks at hand effectively. Think specifically about some of the emotions that may be experienced. These can range from feelings of anger, feelings of loss and the grieving that comes along with it, and perhaps even resentment. Not all of us are equal with adequate coping skills that would allow us to respond to these changes in emotions if we are even able to recognize them. It is important however, to understand that if you are feeling a negative change in emotion that it is wise to consult your physician for advice.

There is one particular thing that caregivers often need but typically have difficulty asking for; and that is help. It is a reflex action for many of us to say we are fine when we are asked how we are doing, but caregivers should not be afraid to let friends, other family members, and even coworkers know of the burdens that they are trying to cope with.

A potentially useful tool that can be considered is the practice of mindful meditation which focuses on having a healthy life and healthy mind and follows a design that is intended to help us put space between our being and our reactions while also helping us breakdown the conditioned responses that we have developed URI-like time. Mindfulness focuses on our ability to be fully present and aware of where we are and what we are doing and allows us to practice the discipline of not being overly reactive or overwhelmed by the things that are going on around us. The ability to do this is something that we naturally possess; however, this practice teaches us to make the skills more readily available on a daily basis. Practicing meditation can be simple. First, we need to make sure that you put the appropriate amount of time aside and find an appropriate space. Once you have done that, take a moment to observe what is happening now while allowing your body to let go of the judgments that have recently been informed about the things that are happening around you. Make note of what your legs are doing and cross them comfortably in front of you if you are sitting on the floor. If you are sitting in a chair, rest the bottoms of your feet on the floor. Next straighten out your body then take note of what your arms are doing and situate them the palms of the hands resting on your legs. Next, soften your gaze by not placing any particular focus on any objects that you may be looking at. Feel your breath and bring your attention to this sensation of breathing and take note of how the air is moving through your nose and mouth. As you are doing all of this try not to have your mind wander on things that may be distracting you, but if that happens do not pass judgment on herself and simply try to redirect yourself to putting your mind at ease while once again trying to rid yourself of those judgments that can be a distraction. After a period of time you can bring yourself slowly out of the state of meditation and resume your normal activities. The potential benefits that can be gained from this type of meditation are numerous including reducing brain chatter, lowering stress, and giving your mind an opportunity to focus.

Elder abuse

Geriatric providers need to be aware of a condition where caregivers can actually make situations worse instead of better. The CDC describes Elder Abuse[5] as an intentional act or failure to act that causes or creates a risk of harm to an older adult. An older adult is someone age 60 or older. The abuse occurs at the hands of a caregiver or a person the elder trusts.

Six frequently recognized types of elder abuse include:

- Physical— occurs when an elder experiences illness, pain, or injury as a result of the intentional use of physical force and includes acts such as hitting, kicking, pushing, slapping, and burning.
- Sexual— involves forced or unwanted sexual interaction of any kind with an older adult. This may include unwanted sexual contact or penetration or non-contact acts such as sexual harassment.
- Emotional or Psychological— refers to verbal or nonverbal behaviors that inflict anguish, mental pain, fear, or distress on an older adult. Examples include name calling, humiliating, destroying property, or not letting the older adult see friends and family.
- Neglect— is the failure to meet an older adult's basic needs. These needs include food, water, shelter, clothing, hygiene, and essential medical care.
- Financial— is illegally or improperly using an older adult's money, benefits, belongings, property, or assets for the benefit of someone

other than the older adult. Examples include taking money from an older adult's account without proper authority, unauthorized credit card use, and changing a will without permission.

Another example of elder abuse although rare is factitious disorder imposed on another (FDIA) formerly Munchausen syndrome by proxy (MSP). FDIA is a mental illness in which a person acts as if an individual he or she is caring for has a physical or mental illness when the person is not really sick.[6] The adult perpetrator has the diagnosis (FDIA) and directly produces or lies about illness in another person under his or her care, while usually a child under 6 years of age, it can occur with older adults. It is considered a form of abuse.

People with FDIA have an inner need for the other person to be seen as ill or injured. It is not done to achieve a concrete benefit, such as financial gain. People with FDIA are even willing to have the patient undergo painful or risky tests and operations in order to get the sympathy and special attention given to people who are truly ill and their families. Factitious disorders are considered mental illnesses because they are associated with severe emotional difficulties.

The Diagnostic and Statistical Manual of Mental Disorders 5, is the standard reference book for recognized mental illnesses in the United States. It describes this diagnosis to include falsification of physical or psychological signs or symptoms, and induction of illness or injury to another associated with deception. There is no evidence of external rewards and no other illness to explain the symptoms.

A person with FDIA uses the many hospitalizations as a way to earn praise from others for their devotion to the child's care, often using the sick child as a means for developing a relationship with the doctor or other health care provider. The adult with FDIA often will not leave the bedside and will discuss in medical detail symptoms and care provided as evidence that he or she is a good caretaker. If the symptoms go away in the hospital, they are likely to return when the caretaker with FDIA is alone with the child or older adult.

People with FDIA might create or exaggerate the older adult's symptoms in several ways. They might simply lie about symptoms, alter diagnostic tests (such as contaminating a urine sample), falsify medical records, or induce symptoms through various means, such as poisoning, suffocating, starving, and causing infection. The presenting problem may also be psychiatric or behavioral.

The recognition of FDIA is especially important as healthcare providers increasing become accountable for the total cost of care given that FDIA results in a waste of valuable healthcare resources for no other purpose but to fill an inappropriate need of the FDIA victim. And while not a form of FDIA there is much more commonly a false perception from caregivers arising from a lack of education that emergency departments and hospitalizations are a needed service when they are not. In the same way with FDIA, this can result in older adults being subjected to unnecessary medical care resulting in poor clinical and financial outcomes. As a result this needs to be addressed at the caregiver level to prevent this waste of resources and more importantly iatrogenic injuries that often occur from unneeded medical services.

Who and how is caring for caregivers

Caring for caregivers typically involves members from the entire care team from nursing, primary care providers, social workers and others. This care can come in the form of providing support, resources and education to support caregivers in this significant role. Part of this support can come in the form of respite or utilization of the hospice benefit.

Respite care can provide temporary relief to a primary caregiver from the continuous support and care of an adult who is elderly or disabled and dependent on others. Services include companionship, involvement in the person's activities of daily living, meal preparation, light housekeeping and personal hygiene tasks. Programs that are at risk for total cost of care often pay for respite care to support caregivers in their role. PACE for example routinely provides caregivers respite in the form of 24/7 home aides or a short stay in a facility, allowing caregivers time away.

Another form of respite is available through the hospice benefit which is typically underutilized. Most research on hospice has focused on the benefits to the dying, but a new study from researchers at the Icahn School of Medicine at Mount Sinai has found that hospice care offers benefits for surviving family members as well.[7] Specifically, when patients in the study received hospice care, their bereaved spouses were more likely to see an improvement in symptoms of depression compared with those who did not.[8]

Hospice users are less likely to experience physical and emotional distress at the end of life, to be hospitalized, to be admitted to the intensive care unit, or to undergo invasive procedures in the last weeks of life. They are more likely to die at home, and family members of hospice users report greater satisfaction with their loved one's quality of care. Despite assumptions to the contrary, some research even suggests that hospice services may prolong life expectancy for certain groups of patients.[5] Furthermore, enrollment in hospice has also been shown to substantially reduce health care costs at the end of life.

Previous research has found some benefit of hospice for caregivers as well. For example, a 2010 study in the *Journal of Clinical Oncology* found that bereaved caregivers of cancer patients were less likely to experience posttraumatic stress disorder or prolonged grief disorder when loved ones died in home hospice care rather than in an intensive care unit or hospital setting.

Benefit of caring for caregivers

Caring for caregivers that care for our patients can have significant impact on clinical and financial outcomes. As such seeing that our patients' caregivers are well cared for can assist us in achieving the outcomes that we are increasingly being held accountable. This is just another example of how factors once considered outside health providers scope is fast become a part of the healthcare teams' role and responsibilities.

References

1. https://www.caregiver.org/caregiver-statistics-health-technology-and-caregiving-resources.
2. AARP Public Policy Institute. (2008). Valuing the invaluable: the economic value of family caregiving.
3. National Alliance for Caregiving and AARP. *Caregiving in the US*. 2015.
4. National Alliance for Caregiving and AARP. *Caregiving in the US*. 2009.
5. https://www.cdc.gov/violenceprevention/pdf/em-factsheet-a.pdf.
6. https://my.clevelandclinic.org/health/diseases/9834-factitious-disorder-imposed-on-another-fdia.
7. http://www.todaysgeriatricmedicine.com/news/ex_080515.shtml.
8. Tao H, McRoy S. Caring for and keeping elderly in their home. *Chin Nurs Res*. 2015;2:31–34.