STUDY SAYS CAREGIVER TEAMS HAVE UNIQUE CHALLENGES

How do caregiving pairs differ in their experience from solo caregivers? Are working conditions improved by the presence of other caregivers, compared to what solo caregivers face? *The Journal of Palliative Medicine* has detailed the results of a study by researchers in California and suggests that team caregivers may face unique challenges, compared to solo caregivers. The report concludes, “Despite assumptions that social support is positively facilitated vis-a-vis collective caregiving, caregiving pairs may be at higher risk for anxiety and depression.”

Caregiving pairs, say the authors, are common in hospice. One might assume that caregiving pairs (informal primary and secondary caregivers working together) would, if anything, boost morale and improve the mental and physical well-being of caregivers. Researchers, however, found that common intuition does not hold up to closer scrutiny. “Although receiving more help from other family members can ease caregiver stress, and caregiver closeness positively impacts the collective caregiving experience, the literature, although scant, reveals contradictory experiences for caregiving pairs.”

Though there appears to be little difference between individual caregivers and caregiving pairs in terms of effectiveness in providing care, “primary caregivers who had secondary caregivers reported more depression and more caregiver burden.” Why should this be so? Some evidence points to the possibility that conflict between caregivers may be a part of the picture. Researchers note, “In collective caregiving, disagreement about family members’ attitude and actions towards the primary caregiver can create greater conflict and greater risk for depression and anger.”

Of equal interest is the disparity that the authors found between primary and secondary caregiver experience. “While secondary caregivers experience less caregiver burden than primary caregivers, they perceive the caregiving situation as more stressful than primary caregivers.” These dynamics vary to a great extent, depending on the unique characteristics of relationships and expectations between family members and other loved ones.

While there are unique challenges and benefits to both solo and team caregiving, this study indicates that team caregiving may correlate with higher levels of anxiety and depression. That being said, they also found many other factors that predicted higher stress levels for caregivers. For example, primary caregivers experienced greater strain than secondary caregivers. Men tended to experience less anxiety and depression than women. “Overall, females report higher levels of depression, exhaustion, and role entrapment associated with caregiving.”
Relatedly, the data indicates that more primary caregivers may be women, while men are more likely to be secondary caregivers.

One acknowledged weakness of this study is that it does not differentiate between primary and secondary caregivers when evaluating reported anxiety and depression. Small sample size is another limitation of the study. The authors call for continued research to shed more light on the unique challenges and benefits faced by team caregivers, both primary and secondary. *(The Journal of Palliative Medicine, 1/10, online.liebertpub.com/doi/abs/10.1089/jpm.2013.0289?journalCode=jpm)*

**ADVANCED CARE INNOVATION IS A KEY TO HEALTHCARE REFORM**

In an article for *Forbes*, Henry Doss presents an interview with Dr. Brad Stuart, “a physician and leader in advanced care innovation.” The interview covers Dr. Stuart’s views of “the outsized role that advanced care plays today from both a cost and patient experience perspective, and how we might change our approach to advanced care.” Over the course of the interview, Dr. Stuart helps to define advanced care, and addresses questions about how to have conversations about advanced care. These discussions force us to face issues of death, dying, and the economic and human costs involved.

To begin, Dr. Stuart takes time to carefully define advanced care as a way of supporting people to pursue life to the fullest. “We are talking about helping people, not patients, get the most out of every minute of life, to support the incredible human capacity to adapt to even the hardest things, to take advantage of the American desire for autonomy.” Stuart explains that the promise of advanced care is to allow people not to think about dying, but about living. “Our job is to support [people’s] living needs, at home and in [the] community.”

Having defined the ultimate objectives of advanced care, Stuart answers questions about how to make these dreams reality, on a practical level. Central to this entire project, he says, is the need for a paradigm shift in how Americans think about health care. “There are just a few conceptual barriers between us and significant innovation, and those barriers are all in how we think about advanced care, not what we do in advanced care.”

Stuart goes on to speak about several of these conceptual barriers, beginning by explaining that the most fundamentally challenging questions of advanced care are not medical but social, cultural and economic. “For example, research shows that 75.0% of heart failure readmissions are due to non-medical factors” such as not being able to fill prescriptions or an inability to afford any kind of care besides going to the ER. Dr. Stuart concludes that a truly effective system must be one that is “anticipating problems, providing support, and bringing medical treatment to people where they live.”

While Dr. Stuart repeatedly emphasizes that hospitals are not the problem, he points out that much of the care that is currently delivered to seriously ill people in hospitals could be provided with higher quality of life in the context of patients’ homes. “A big part of dealing with advanced illness in a more cost-effective and compassionate way is developing models that
deliver at-home care, and that help those with chronic illnesses stay out of the hospital and out of recurring treatment cycles.”

Above all, Stewart emphasizes that we should never be faced with a choice between high-quality care and reducing expenses in the system overall. The solution, as repeated by Stuart throughout the article, is innovation. “I strongly believe that real innovation in healthcare delivers a better experience at a lower cost - both at the same time.”


**HOSPICE NOTES**

* Looking to invest in hospice and palliative care? *PR Web* predicts strong growth over the next five years, but says, “Hospice care centers have recently come under public scrutiny for fraudulent enrollments.” Noting the increased government oversight on the hospice care industry, “growth is expected to remain below its potential over the next five years.” Even lower growth is predicted for after 2019. (*PR Web*, 2/7, www.prweb.com/releases/2014/02/prweb11563805.htm)

* Who’s the biggest loser when a patient gets referred to hospice? It might be the referring physician, suggests James Salwitz, MD. “For many doctors who fight fatal diseases month after month... the loss of connection [with patients] is draining.” (*Sunrise Rounds*, 1/31, sunriserounds.com/neglected-hospice-patient/)

* The US Department of Health and Human Services, Office of Inspector General, issued the work plan for fiscal year 2014. The report clarifies that hospice offers palliative rather than curative care and that hospices assume responsibility for all care related to the “beneficiary’s terminal illness and related conditions.” The report identifies two specific areas of care it intends to review. The first is the use of hospice general inpatient care. CMS will “assess the appropriateness of hospices’ general inpatient care claims and the content of election statements for hospice beneficiaries who receive general inpatient care” and “will also review hospice medical records to address concerns that this level of hospice care is being misused.” The report also identifies hospice care in assisted living facilities (ALFs) as an area for review. OIG says it will “determine the length of stay, levels of care received, and common terminal illnesses of beneficiaries who receive hospice care in ALFs,” citing that MedPAC has “said that these long stays bear further monitoring and examination.” (*OIG Work Plan*, February 2014, oig.hhs.gov/reports-and-publications/archives/workplan/2014/Work-Plan-2014.pdf)
* A local hospice program seeks healing through artistic expression. Hospice of Hope is using art in bereavement groups to bring comfort to those grieving the loss of a loved one. *(The Ledger-Independent, 2/6, maysville-online.com/news/local/hospice-program-offers-healing-through-art/article_58a848bc-3624-54ef-aeb9-50f264720fc7.html)*

* Is it time for end-of-life care to move beyond hospice? Janice Lynch Schuster suggests that there are serious shortcomings in the US hospice system as currently designed. The Medicare Hospice benefit works well for some, she says. Others, especially those dying in ways that do not fit into the assumptions of the system, are not as well served. *(Alatrum, 2/6, altarum.org/health-policy-blog/beyond-hospice-end-of-life-care-for-the-21st-century)*

* AcademyHealth’s Translation and Dissemination Institute has published results of a “Listening Project” focused on “identifying the most pressing health services research needs of leaders in health policy and health care delivery for the coming three to five years.” The study’s report is based on interviews with health policy leaders, experts and analysts from government agencies. The report mentions hospice care, saying, “Of particular interest is research on the Medicare hospice benefit, including a better understanding of who uses it, for how long, and with what impact on costs and quality of care/life.” The complete study is online for review. *(AcademyHealth, academyhealth.org/files/publications/listeningprojectmedicare.pdf)*

END-OF-LIFE NOTES

* Allen Klein is a speaker who focuses on helping people learn how to laugh in the face of some of life’s most difficult moments. “Klein’s aim is not to entertain, but to help people use humor to deal with life’s most stressful situations.” *(Psychology Today, 1/9, www.psychologytoday.com/blog/changing-the-way-we-die/201401/when-life-gives-you-death-whats-so-funny)*

* “Disenfranchised grief” - grief that is not supported in the workplace - is common among health care chaplains, according a survey carried out by Steven Spidell in 2009. For some, grief is a “constant companion,” writes Kristin Lindholm Gumminger. *(Religion News Service, 2/5, www.religionnews.com/2014/02/05/chaplains-help-others-grieve-learn-grieve/)*

PALLIATIVE CARE NOTES

* How can professionals best communicate with family members when making an assessment of patient condition? A study published in *The Journal of Palliative Medicine* concludes, “Training in conversation skills could be one way to support professionals when discussing and managing these difficult situations.” *(The Journal of Palliative Medicine, online 1/30, online.liebertpub.com/doi/abs/10.1089/jpm.2013.0507utm_source=FastTrack&utm_medium=email&utm_campaign=jpm)*
* Palliative surgery for malignant bowel obstruction can sometimes do more harm than good. “Palliative surgery for malignant bowel obstruction caused by peritoneal metastases can be helpful but presents no easy choices for patients or practitioners, according to a new paper published in JAMA Surgery. (JAMA Surgery, 1/29, http://archsurg.jamanetwork.com/article.aspx?articleid=1816003)

OTHER NOTES

* Edith Tarbescu writes about her experience of being a caregiver for a loved one who, suffering leukemia-related pain and facing another trip to the hospital, decided to end his own life with a gun. Tarbescu connects this deeply personal experience with the public debate around physician-assisted suicide. She encourages readers to “seriously discuss the issue of assisted suicide.” (The Courant, 1/31, www.courant.com/news/opinion/hc-op-tarbescu-physician-assisted-suicide-or-a-gun-20140131,0,5175680.story)


* There is a growing need to protect working caregivers, says Jim Fitzgerald of The Associated Press. “If you don’t get a job because you’re a woman, or you get fired because you’re black, or you get transferred to the night shift because you’re gay, there’s a law for that. But if you’re punished at work because you need time to take your child to the doctor or talk to your confused elderly mother, you might be out of luck.” (Chicago Sun-Times, 2/3, www.suntimes.com/lifestyles/25357843-423/a-growing-need-to-protect-the-working-caregiver.html)


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