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## When the going gets tough: caregiving and abuse

By Mary Twomey

sk any new mother, and you'll learn that among the materials she received when leaving the hospital with her newborn was information about Shaken Baby Syndrome and child abuse. Designed to alert new parents to the warning signs of child abuse, the materials do not judge parents for the frustration or anger they feel when, say, their baby won't stop crying, they just send a clear message that child abuse is unacceptable, explain its consequences, provide tips on how to handle their feelings and information on where to turn for help. And such materials work, according to a study by Barr et al., published in the *Canadian Medical Journal* (180:7, 2009, <a href="http://goo.gl/QBKXSH">http://goo.gl/QBKXSH</a>).

Now, ask any new caregiver of an elder or adult with a disability and they will tell you no one has ever spoken to them about the warning signs of abuse and neglect. They come home from hospitals or doctors' offices with information about medical conditions, medications and such, but nothing they receive tells them that one in 10 community-dwelling older Americans becomes a victim of abuse or neglect, according to the 2010 National Elder Mistreatment Study (http://goo.gl/7HHLHh).

Nor does anyone warn them about how aggressive some care recipients can be toward those providing care. Not surprisingly, research shows that for every case of elder abuse that is reported to authorities, 23 are not reported, according to *Under the Radar: New York State Elder Abuse Prevalence Study (http://goo.gl/a2Qraz*, 2011). By hiding the issue, we don't make it safe for caregivers to talk about their feelings or to reach out for help when the going gets tough.

## **Talking with Caregivers about Abuse**

Starting a discussion with caregivers about elder abuse is a delicate task, but research shows that it's one well worth having. In a study done by the University of California, Irvine, caregivers of community-dwelling people with dementia were asked whether or not they had ever engaged in abuse, and 47 percent revealed that they had been abusive to the elder in some way.

What environment had the researchers created that enabled so many caregivers to feel comfortable talking about abuse? Could it be caregivers are willing to talk, but no one is asking them? General statements like: "I see so many caregivers who are at the end of their rope that I now ask everyone, how are *YOU* doing?" or, "I don't know if this is a problem for you, but I see so many caregivers who feel like striking out or yelling at the person they are providing care for ..." can be a useful way to start an honest conversation.

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## The Risk Factors for Abuse

Exploring research on risk factors that predict abuse is also helpful. Caregiver characteristics associated with mistreatment include higher anxiety, more depressive symptoms, fewer social contacts and greater perceived burden. Care recipients who are isolated, have cognitive impairment and who themselves are physically or psychologically aggressive are at greater risk for abuse, according to Wiglesworth et al. in an article in the *Journal of the American Geriatrics Society* (58:3, 2010, http://goo.gl/p5agTD).

In the U.K., Cooney, Howard and Lawlor found the following to be associated with mistreatment: carers with greater levels of expressed emotion and higher ratings of psychological distress, as well as patient agitation, irritability and communication difficulties, as described in their article in the *Journal of Geriatric Psychiatry* (21:6, 2006, http://goo.gl/BvON6U).

These risk factors may inform us when making caregiver assessments. If assessments evaluate for these predictors of abuse, the care plan should reflect a realistic understanding of red flags and address them before abuse or neglect take place. Caregiver support programs like REACH (Resources for Enhancing Alzheimer's Caregiver Health) have been shown to reduce the rate of certain risk factors associated with caregivers, such as depression and anxiety, according to several trials described in the Caregiver Intervention Database at the Rosalynn Carter Institute for Caregiving (http://goo.gl/pvKCeA).

## **Professionals Need Familiarity with Resources**

Sadly, funding for state and federal caregiver programs has not kept pace with costs and demand, and in many cases has been decreased in the past five years. State and federal efforts for prevention and intervention of elder abuse are historically significantly underfunded, which the Government Accountability Office pointed out in its 2011 report, *Stronger Federal Leadership Could Enhance National Response to Elder Abuse (http://goo.gl/yvzGHU)*. Professionals should know the resources to help caregivers (e.g., Family Caregiver Alliance, Alzheimer's Association, National Alliance for Caregiving), as well as resources for abuse victims, including Adult Protective Services (http://goo.gl/K76005) and the Long-Term Care Ombudsman Resource Center (http://goo.gl/uCzPg6).

Looking ahead, we must more fully integrate the topic of elder abuse into the national conversation about caregiving, and explore ways for the elder justice community to support caregivers. We need more research to examine what factors correlate to abuse by caregivers and we need to create evidence-based models of prevention and intervention.

When it comes to keeping older Americans free from abuse, there is no "us" and "them." As Rosalynn Carter said: "There are only four types of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."

Mary S. Twomey, M.S.W., is co-director of the Center of Excellence on Elder Abuse and Neglect at the University of California, Irvine. For information and resources, visit www.centeronelderabuse.org.