

Compound Caregivers: Overlooked and Overburdened

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Compound Caregivers: Overlooked and Overburdened

Elizabeth A. Perkins, PhD, RNMH, July 2011

I am a 51-year-old mother of my 31-year-old daughter who has intellectual disabilities. She also has End Stage Renal Disease and undergoes peritoneal dialysis nightly. In addition to supporting my daughter's needs, I also assist my husband who has Advanced Macular Degeneration which leaves him unable to drive, read or do anything requiring acute visual abilities. My 73-year-old mother has also recently moved into my household from out-of-state on a temporary basis following the death of my father. Though her current situation is (hopefully) temporary, she will be moving within close proximity of me so that I can also assist her when needed.

Due to my many caregiving obligations, I am unable to secure a job outside the home to help with finances or add to my own retirement savings. I have a college education that I have been unable to take advantage of for the past eleven years. My greatest concern is for my family member's wellbeing should I develop my own medical issues. We do not take vacations, we rarely visit with our other children and grandchildren who live a distance away due to my daughter's dialysis needs, and even my ability to volunteer with various organizations (which was a much-loved social activity) has also been greatly diminished. My whole life has become my caregiving roles—there is simply no time for anything else.

- A Compound Caregiver, Florida

The recent position paper by the Rosalynn Carter Institute for Caregiving, “Averting the Caregiving Crisis: why we must act now”¹ details the growing concern of escalating needs for family caregiver services across the nation. This rise in demand and assistance required is a result of an increasingly aging population of older adults (especially the baby-boomer generation), increased longevity, and the increased duration of long-term management of aging-related chronic health care conditions.¹ These factors strain an already overburdened formal healthcare system that simply lacks the resources needed for adequate provision and assistance.¹

The collective contribution provided by caregivers to support the health and well-being of individuals with disabilities and/or chronic health issues is substantial.

The economic value of family caregivers, were they to be paid for the services they voluntarily undertake, was estimated in 2006 to be \$350 billion.² To compare—total Medicare expenditure for the same year was \$374 billion.³ Clearly the national ramifications that would arise if this voluntary workforce of caregivers did not exist would be nothing short of catastrophic, especially for the millions of people that rely upon them.

The widespread acknowledgment for their importance in bolstering the formal health care system of the nation has led to the increasing recognition of caregivers' own health as a major public health issue.⁴ By safeguarding the health and well-being of caregivers, it allows them to continue in their caregiving roles and thus delay institutionalization and out-of-home placements of their care recipients

(i.e. those who are supported by caregivers). Care recipients can be very diverse—in terms of their ages, cognitive disabilities, physical disabilities, mental health needs, and physical/chronic health needs. Thus, it is vitally important to be aware of the variety of contexts across the lifespan in which caregiving responsibilities can occur.⁴ This is especially true when considering services and the impact of policies designed to capture and assist many types of caregivers as, unfortunately, there are still circumstances that have yet to be recognized appropriately.

Within the caregiver population, older caregivers of adults with intellectual disabilities (ID) are a unique group.⁵ They face circumstances and challenges that are quite distinct from caregivers of persons that have developed illnesses, or acquired disabilities from accidents or trauma. These challenges include the fact that their caregiving role has been a lifelong endeavor⁶, and thus they face lifespan health issues that arise from their care recipients' often complex aging process⁷, as well as their own aging process/illnesses. Furthermore, unlike most other caregiving roles which cease upon the death or diminish after transfer to a long term care setting of the care recipient, caregivers in these circumstances often continue caregiving until their own incapacity or death. Thus, there is an added anxiety regarding the future welfare of adult sons or daughters with intellectual disabilities when the caregiver is no longer alive or able to provide care.⁶

The Growing Issue of Compound Caregiving

The term “sandwich caregiving” refers to those people who undertake caregiving responsibilities for one or both of their aging parents while still having parenting duties to their own children.⁸ Sandwich caregiving is a common and sometimes difficult issue, and the potential duration of being a sandwich caregiver is increasing due to the combination of baby boomers who delayed the average age of having their own children, and their parents' increased life expectancy.⁹ For many who find themselves in the sandwich generation—their child can actually be helpful and supportive to completing tasks and duties the parent performs as a caregiver.

However, there are substantial differences between those sandwich caregivers and caregivers who are parents to adult children with intellectual disabilities. *Compound caregiver* refers to those parents who are already providing considerable caregiving responsibilities to their son/daughter with ID, who subsequently becomes a caregiver for an additional family member.¹⁰ Their caregiving duties are effectively compounded by their additional caregiving roles, especially as their son/daughter may be unable to give any substantive assistance to the additional care recipient.¹⁰ Furthermore, periods of compound caregiving may actually occur several times, and may occur not just for parents, but parents-in-law and siblings, in some cases.^{10, 11} The increased life expectancy of persons with ID¹², and the general population, will likely result in compound caregiving becoming a circumstance that more aging caregivers of adults with ID will experience. As little as 30 years ago, parent caregivers routinely survived their adult children with ID, but now this is no longer the case. Persons with mild ID enjoy a similar life expectancy as the general population, and individuals with moderate/severe ID can also expect to live into their late 60s and late 50s respectively.¹² Thus, as approximately 85% of all individuals with an intellectual disability have mild ID (the other 15% having moderate/severe/profound ID)¹³, an increasingly aging population of adults with intellectual disabilities will now routinely survive their parents. More than ever before, caregivers are now destined to be caregivers for their own entire lifetime, or be “perpetual parents”.¹⁴ As parental caregivers continue to provide the majority of care to adults with ID¹⁵, the experience of compound caregiving for others appears to be cause for great concern.

Why the Cause for Concern?

In general terms, it appears that a substantial number of caregivers are actually caregivers to more than one care recipient. The National Alliance for Caregiving and AARP survey recently reported some 34% of caregivers were regularly providing care to more than one person.¹⁶ The present system largely ignores the possibility of multiple caregiving roles and the complexity of such circumstances. Preliminary research¹¹ has indicated that “compound caregiving” might be as commonplace in

Spotlight on Aging Compound Caregivers in Florida

those who support adults with ID as those in the general caregiving population who support more than one care recipient.¹¹ In a recent study¹¹ of 91 caregivers (aged 50+), 37% were current compound caregivers. Furthermore, 66% either were presently or had previously been a compound caregiver and 34% anticipated needing to be a caregiver to a specific family member in the future.¹¹ Thus, compound caregiving is a life course issue that many aging caregivers may cycle in and out of several times.¹¹ It therefore appears that family caregivers of adult children with intellectual disabilities are actually no less likely to become caregivers to other family members.

The same study found that the current compound caregivers had been in their present dual caregiving roles an average of three years.¹¹ Most were caring for their own parents, spouses, or siblings, who had chronic conditions such as Alzheimer's disease, cardiovascular disease, Parkinson's disease, and general frailty.¹¹ Although this preliminary study¹¹ did not find significant differences in levels of life satisfaction and physical and mental health when comparing compound caregivers with non-compound caregivers, compound caregivers did report an increased desire to place their son/daughter with ID into an alternative residential setting. It may reflect that a tipping point has been reached from the multiple caregiving demands that results in feelings of burden and inability to cope.

Compound caregivers described several major problems in performing multiple caregiving roles—including: inadequate help, feeling physically tired, emotionally stressed, and the restriction placed on their own life and activities.¹¹ This is not surprising when these compound caregivers reported spending an average of 52 hours a week fulfilling the duties of their combined caregiving roles. It is also important to note that a caregiver who begins caregiving duties for a parent/spouse, in many cases has simultaneously lost someone who may have actively assisted them in caring for their son/daughter with ID. Compound caregiving is an underexplored life circumstance. However, other types of caregivers who are also long-term caregivers (e.g. caregivers to those with chronic mental health issues, or chronic physical health issues, or those with significant physical disabilities) are also likely to have similar challenges.

There is a current but long-standing funding crisis nationwide in supporting adults with ID to live independently, or to fully support family caregivers when adults with ID continue to reside in the family home. Most adults with ID continue to live with their aging parents, relying on various types of informal and formal supports, mainly utilizing Developmental Disabilities Home and Community Based Services Medicaid waivers. Florida—due to its higher percentage of older adults—is at the forefront of this emerging issue of compound caregivers. Highlighting these emerging issues in the context of Florida serves to illustrate that other states will also be dealing with similar issues regarding their aging caregiver population and aging population of older adults with ID who co-reside with their family.

In Florida, the Agency for Persons with Disabilities (APD) currently provides services to approximately 35,000 individuals with intellectual and developmental disabilities, but a further 19,000 eligible individuals are currently on APD's waiting list. The waiting list has 7 categories¹⁷, the first two are for individuals in crisis, or dependent children in foster care. Category 3 is when needed caregivers will be unable to provide care within the next 12 months, or the applicant is at high risk of incarceration or receiving Voluntary Protective Services.¹⁷ Category 4 stipulates caregivers are age 70 or older and no alternate caregiver is available.¹⁷ The remaining three categories are for those graduating secondary school and require support to obtain employment, or are 21 and older and don't meet eligibility of the previous categories, or are under 21 and do not meet eligibility of the previous three categories.¹⁷

Currently, only those who are assessed to be in the first two categories are immediately granted services.¹⁷ Though it is encouraging that the needs of older caregivers are essentially recognized in categories 3 and 4, the fact that this is a waiting list category—emphasizes that there are older family caregivers who are struggling with waiting for services. Similar categories for waitlist prioritization towards older caregivers or change in caregiver status (e.g.

usually the caregivers' illness and incapacity to continue the role) are evident throughout the United States.

In Florida, some caregivers have found themselves in this situation for most unfortunate of reasons. These include older parents who relocated to Florida to retire and were not aware that there is no portability of their adult child's Medicaid HCBS Coverage. Thus, an eagerly anticipated retirement in the sunshine state did not materialize, and some older caregivers are spending significant amounts of time and their retirement savings to provide meaningful activities to their adult child with ID. Given the current economic recession and precipitous decline in the housing market, some older caregivers are essentially "trapped" in Florida—unable to return to the state where their son/daughter previously received services. Fundamental changes to the breadth of coverage of services provided seem increasingly unlikely in the current economic climate. Indeed, even for those caregivers who have children with ID and currently receive services, the future security of receiving the same level of supports is absent in many cases, adding to the considerable angst already felt by these aging families.

Unpublished data from the sample of caregivers studied in the Compound Caregivers study¹¹ revealed that 28% of the caregivers whose sons/daughters were on the DD HCBS waitlist were actually compound caregivers. Having no support is already a challenging circumstance, but add another caregiving role into this equation and clearly there is grave risk for caregiver stress/burnout.

"I believe that I was quietly fuming that others were not seeing the unimaginable burden I was bearing. When I think back now, I realize that I was apprehensive about acknowledging that I needed help, let alone asking for it."¹⁰(pg. 251)

Recommendation: Waitlist Prioritization Categories

It is not enough to base prioritization of caregivers on their age alone. There is also a need to include caregivers who find themselves with compound caregiving roles.

An aging caregiver must, absolutely, be supported, but a compound caregiver in their 50's and 60's might actually have more onerous caregiving responsibilities with less support. Their circumstances also need to be recognized and appropriate support offered.

Recommended Solution to Florida's Waitlist Prioritization:

Categories 3 and 4 of Florida's APD waitlist, which refer to aging caregivers aged 70+, should also include all compound caregivers (aged 50+). This will ensure that compound caregivers are being assessed and recognized in the waitlist prioritization process.

Recommended Nationwide Solution for Waitlist Prioritization:

Any existing references to aging caregivers for prioritization in waitlist categories should also include compound caregivers (aged 50+). States that do not currently identify aging caregivers as a population for waitlist prioritization—should incorporate both aging and compound caregivers.

How to Directly Address the Problem of Caregiver Support?

Against the backdrop of shrinking resources for direct services towards persons with ID, an alternative method is to advocate for greater support to caregivers in terms of respite care. The advantage to this approach is that there are substantial number of caregivers in the general population whereas, comparatively speaking, relatively few family caregivers of adults with ID. It is the opinion of the author that any fundamental improvement to caregiver support is best served by being appropriately recognized within the "general" caregiver framework rather than outside of it.

Respite Care

The value of respite care is that it gives the care recipient a break from their continual caregiving responsibilities. Its value lies in the caregiver undertaking duties/hobbies/activities that are sidelined when providing care to another. It allows the caregivers to rest and focus on other family relationships and their own needs. With adequate respite, the risk of "role overload"—a feeling that one's

life is all about the caregiving role and responsibilities—is minimized. Some caregiving tasks can be physically and psychologically demanding. Thus, in order to avoid “burnout,” respite is crucial to receive.

Compound Caregiving and Respite Care

If a caregiver receives respite care, but still has extensive caregiving responsibilities for another, the true benefit of respite care service is unrealized. Situations may arise where a provider is providing respite care to one care recipient, but is not allowed to provide respite to the other care recipient in the same household. Therefore, the caregiver is temporarily relieved of one caregiving role, but not the second. It effectively renders the received respite care to being little more than assistance—not true respite relief.

The Need for Creative Combination of Services to Consolidate Respite Care

There are obvious advantages to combining and coordinating aging and disability services to enable periods of simultaneous respite support of multiple care recipients. The respite care would be more effective in giving the caregiver a total break. Additionally, as the respite received is more beneficial, the perceived burden of care would be reduced, buffering the psychological and physical well-being of the caregiver. The tangible health benefits aside, the actual number of hours independently required for each care recipient is reduced, leading to overall reduction in cost implication for the respite service itself, as well as administrative and logistical savings.

How to Increase Existing Provision for Respite Care

a) Expand eligibility of the Older American Act—Title III E—National Family Caregiver Support Program to include older caregivers of adults with ID. Currently the program supports caregivers of any age who support care recipients aged 60+, or family caregivers aged 60+ who are caregivers to children aged 18 or younger. Thus, caregivers who provide substantial help to their adult children with ID are not eligible to receive caregiver support services under this program. As family caregivers are often lifelong caregivers, it is unfair that, with their increasing age, they are not able to access the resources and trainings provided by this program.

b) Increase funding for the Lifespan Respite Care Act of 2006. The major goals of the Lifespan Respite

Act were to expand and enhance availability of respite services, improve coordination, streamline access, and improve the quality of existing services. Furthermore, states are to serve families irrespective of age or special need. Unfortunately, it has been chronically underfunded. Originally, the law was authorized at \$30 million in FY 2007, \$40 million in FY 2008, \$53.3 million in FY 2009, \$71.1 million in FY 2010, and \$94.8 for FY2011. However, the first appropriation did not occur until FY 2009. The actual appropriation was a fraction of the authorized amount, at just \$2.5 million in both FY 2009 and FY 2010. Without a substantial increase in funding, projects currently funded under this act will be sporadic across states, be unlikely to move beyond pilot/demonstration projects, and will therefore lack sustainability to build nationwide capacity.

c) Fund Title II—Family Support of the DD Act 2000. Title II of the DD Act authorizes the Family Support Program in order to promote the implementation of comprehensive state systems for effective in-home supports to families caring for individuals with disabilities, with the goal of reducing expensive out-of-home placement. Though the philosophical value of such support has long been recognized, Title II has never been funded. Line item funding is urgently required, not just to increase the possibility of funding Title II, but to receive funding that would actually support projects of significant scope and impact. Priority should be given to projects that support aging and compound caregivers.

Further Research and Practice Recommendations

Research

Further research to identify the extent of compound caregiving and longitudinal trajectories of compound caregiving are urgently required. Comparison of health outcomes of compound caregivers who have care recipients with long-term chronic health conditions and dementias are also needed. Effectiveness of respite care programs for compound caregivers also needs to be evaluated.

Practice

Assessment for support services requires re-examination. Any assessment of caregiver supports provided should fully consider and note all caregiving roles currently undertaken in determining service provision and eligibility. There also should be a rapid mechanism to respond to changes in a caregiver's evolving circumstances in the services required. This way additional support can be provided, but also withdrawn when the compound caregiving duties cease.

Final Comments

Compound caregiving is a reality for many caregivers, and particularly aging caregivers of adults with ID. These caregivers have already devoted a lifetime to support their child and, in many cases, have had to do so with less than optimal support from formal service providers. As these caregivers face their own aging and health issues, they concurrently face additional caregiving duties to other family members. Clearly, in terms of additional/prioritized supports, compound caregivers are a unique group of caregivers who deserve special recognition from researchers, policy makers, and providers alike. As a society, is it really an acceptable state of affairs when their own life's ambitions, wants, and needs are subsumed to the needs of others? It is time to redress the balance of what is acceptable in our society and to provide better types of support to individuals in these circumstances.

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