The Economic Value of Youth Caregiving in the United States

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Abstract: Although studies estimate the annual cost of informal family caregiving by adults, no estimate exists for the informal caregiving undertaken by youth. The objective of this analysis is to provide a profile of these young caregivers and an economic perspective on the importance of youth caregivers’ contributions to their families and communities. Our overall goal is to enhance the knowledge and advocacy of educators and policy makers on behalf of these unrecognized helpers by providing one measure of how important their contributions are and will continue to be.

Introduction

Studies of informal caregivers in the United States have traditionally been directed towards the 65.7 million adult caregivers who provide care to spouses, parents, friends or children (NAC/AARP, 2005). At the other end of the caregiving spectrum are the estimated 1.3-1.4 million youth caregivers, ages 8-18 years, who provide assistance for parents, grandparents, and/or their disabled siblings and other relatives, and whose contributions remain undocumented, unrecognized and virtually invisible (NAC/UHF, 2005).

Becker (2007) comments in his global typology of youth caregiving that there have been no estimates made in any country of the hidden economic or social costs of children’s unpaid care work. Young caregivers are ‘invisible in our society’ despite studies from the United States, United Kingdom, Australia, Canada, and Africa which suggest a growing reliance on youth caregivers and the need for policies to support family caregiving needs (Becker 2007; Charles, Marshall & Stainton, 2010; Orel & Dupuy, 2002; Siskowski 2004). These studies also confirm that youth caregiving is not an uncommon experience for our young people and appears to be a “normal experience for a small but significant percentage of young people” (Charles, Marshall & Stainton 2010).

The Burden of Being a Young Caregiver

Among child caregivers, it may be that as many as one-third care for those between the ages of 40 and 59, usually a mother with a chronic disease (NAC/UHF, 2005). The burden of care for these young people can often be as challenging to them as it is for an adult caregiver of an aging parent. For example, adult caregivers help with an average of four to five instrumental activities of daily living (e.g., preparing meals, shop-
ping, doing housework), a burden matched by 40% of older youth caregivers, ages 12-18 (NAC/UHF, 2005; NAC/AARP, 2009).

It is well established that the average hours of total care provided by adult caregivers is about 20 hours per week (NAC/AARP, 2009). A review of the literature of teens’ time spent on housework and chores, including babysitting siblings and providing elder care, has been estimated to range from 13-17 hours per week for girls and 9-13 hours per week for boys (Gager, Cooney, & Call, 1998). Perhaps surprisingly, youth caregiving is evenly distributed between boys and girls (Charles, Marshall & Stanton, 2010; NAC/UHF, 2005). Data on elder care from the Youth Development Survey indicate that 4-8% of youth respondents (14-18 years old) reported providing, on average, 2.9 to 3.9 hours of elder care per week (Mortimer, personal correspondence, 2010).

Youth and adult caregivers both can suffer adverse health impacts as a result of their caregiving burden. Among caregivers, 31% of adults, 58% of children 8 to 11 years old, and 61% of children 12 to 18 years old report stress, anxiety or depression as a result of their caregiving responsibilities (NAC/AARP, 2009; NAC/UHF, 2005). Levels of anxiety and depression are higher in youth caring for family members in the home than out of the home (Cohen, Greene, Toyinbo & Siskowski, in press). Seventy percent of adult caregivers report making work accommodations due to caregiving demands, and 53% report time lost with friends and family.

Nearly half of youth caregivers report not submitting a homework assignment at school, and 20% report missing school or an after-school activity (NAC/UHF, 2005). A 2002 survey of students in 54 middle and high schools in Palm Beach County, Florida found that 56% of students reported that they provided hands-on care for a family member, and among those, more than two-thirds reported that assisting with their relative’s care had a negative impact on their academic performance (Siskowski, 2004). Additionally, among these student caregivers, more than 35% reported that it interrupted their ability to study, 25% said they were unable to complete homework assignments and 18% reported two or more negative effects of caregiving on their academic performance.

In a recent review of 11 qualitative studies of youth caregivers, Rose and Cohen (2010) conclude that the impact of caregiving on our young must be recognized as they cope with ongoing stress and struggle to “integrate caring into their emerging identities.” Caregiving affects young people’s leisure time, social experiences and networking (Barr, 2011). Caregiving is not child’s play!

The Value of Informal Youth Caregiving

The objective of this analysis is to provide an economic perspective on the importance of youth caregivers’ contributions to their families and communities. The economic value of youth and adult caregiving is based on the approach by Arno and colleagues (1999). Caregiving prevalence data are derived from sources such as the National Youth Caregiver Study (NAC/AARP, 2009) and the Youth Development Survey (NAC/UHF, 2005). The economic value of informal caregiving is estimated using various methods, including the Lost Opportunity Method and the Market Valuation Method. The Lost Opportunity Method involves estimating the value of the time spent by caregivers in providing care, while the Market Valuation Method involves estimating the market value of the goods and services provided by caregivers.

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From two surveys, Caregiving in the U.S. 2009 (NAC/AARP) and Young Caregivers in the U.S. 2005 (NAC/UHF), wage rates are based on the 2009 MetLife Mature Market Survey of Nursing Home, Assisted Living, Adult Day Care Services, and Home Care Costs and the Bureau of Labor Statistics. Of the $350-$450 billion dollar estimated annual value of informal caregiving (Arno & Viola, 2009; Feinberg, Reinhard, Houser & Choula, 2011), approximately 2.4%, or $8.5 billion dollars, is the estimated value of youth caregiving in the United States. However, this estimate is conservative. It does not take into account the value of youth caring for disabled siblings, nor does it account for any long term impact that youth caregiving may have on future wages, employment or savings. Finally, it relies upon the one U.S. youth caregiver prevalence survey which is also an underestimate. As seen in the chart above, informal caregiving in the United States is worth more than national expenditures on home care and nursing homes combined.

Conclusion

The United States is in the preliminary stages of awareness, understanding, and research with respect to its young caregivers. There are no specific legal rights or policies on behalf of youth caregivers, nor are there any national services that provide assistance for them. This is in sharp contrast to the United Kingdom, where there is widespread recognition, research, and established legal rights, policies, programs, and services available on behalf of this group (Becker, 2007).

As we advocate for reform, legislative and policy initiatives must consider the different consequences for adult and youth caregivers. For example, youth caregivers need policies that provide assistance and support for them in their two work places: school and home. Health care providers must learn to recognize their role and include them in discharge and home care planning. Pediatric health professionals must be knowledgeable about the physical and psychological effects of caregiving by youth and incorporate the identification of this role in their everyday practice. Young caregivers may need to participate in their siblings individualized education or service plan if they are participating in the home caregiving team and these youth caregivers need support programs that recognize their needs as well as the needs of their impaired family members.

The Caregiving Youth Project (CYP) in Palm Beach County, Florida, under the auspices of the American Association of Caregiving Youth, is the only program in the United States dedicated to education, support and services to youth caregivers and their families (Barber and Siskowski, 2008). CYP services provided at school, at home, and in the community have a direct positive impact on students with family caregiving responsibilities and their family members (Cohen, Martinez-Tyson, & Greene, 2011). The CYP improves their abilities as caregivers, successful performance at and remaining in school, as well as their confidence and self-esteem as developing adolescents. Family members also report observing these changes in their children’s attitudes and behaviors. Priorities for future youth caregiver research should focus on risk and protective factors affecting physical and emotional health of children and their families, the impact on child and young adult development, the impact on educational and occupational success, and interventions to support the health and well-being of youth and families (Cohen, Greene, Toyinbo, & Siskowski, in press). Coupled with the economic value of the care contributed by these young caregivers during their childhood should be a high return on investment when dollars are spent wisely to support these children to ensure their future as productive adults.

The United States must do for youth caregivers what organizations have begun to do on behalf of adult, informal caregivers, to create a more rational and equitable way to distribute the growing need for care in our society.
References


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