Impacts of Caring for Children with Medical Complexity on Parents’ Employment and Time

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BACKGROUND

• Growth in the population of children with medical complexity (CMC) and accompanying increases in utilization have focused attention on costs and savings for institutions.
• Few studies have yet focused on the costs of family care of CMC in terms of employment and time.
• Most studies of the impacts of caring for children with disabilities on families only include mothers’ experiences.
• Studies of families of children with disabilities suggest that it is likely to be those families with the fewest resources who will incur the greatest costs of care.

OBJECTIVES

• This study characterizes families of CMC with respect to their experiences of employment loss and career impacts for the primary caregiver (PCG) and spouse, amount of time that the PCG spends providing care, and how these experiences differ by socioeconomic status, as measured by PCG education.

DESIGN & SAMPLE

• Cross-sectional mail survey design: advance postcards, pre-incentive ($10), reminder postcards, and post-incentive ($25); fielded by UW Survey Center Oct 2011 – Feb 2012.
• A total of 98 of 155 (64% response rate) PCGs of CMC enrolled in a tertiary center care coordination program (Special Needs Program [SNP]) at the Children’s Hospital of Wisconsin.
• 92% women, 80% married/living with partner, 89% white.
• Mean age of PCG: 39 yrs. (range 21-65).
• Education: 19% <HS, 42% some coll./voc. cert., 39% ≥ college.
• Half of PCGs employed (32% FT, 18% PT).
• Mean age of CMC: 7 yrs. (range 0.5-20).

MEASURES

• Employment Loss: left job voluntarily or involuntarily; lost business; reduced hours; took leave of absence; gave up working altogether; or retired earlier than planned due to demands of parenting child with special needs.
• Negative Career Impact: took less demanding, lower-paid, or less interesting job; lost opportunity for promotion; or turned down promotion due to demands of parenting child with special needs.
• Loss of income: lost income or wages due to demands of parenting child with special needs.
• Increased Work: increased paid work hours; took more demanding, higher-paid job due to demands of parenting child with special needs.
• Time spent providing care: “During [shift], how many hours did you spend directly performing tasks related to a child’s care or making sure someone else is providing care? In other words, a spouse, partner, Personal Care Attendant, nurse, therapist, etc. may be there for a child, but the caregiver instructs, manages, and provides care overall.”

RESULTS

• PCGs reported substantial impact on their employment and career and that of their spouses/partners due to the demands of caring for their CMC.
• Reports of PCGs’ employment loss, negative career impact, and increased work were quite consistent across PCG education level, but more educated PCGs were more likely to work.
• Approximately half of PCGs reported spending large blocks of time (“shifts”) providing care for their CMC during the typical workweek, that is, Monday through Friday. Higher proportions of PCGs reported caring during these shifts on weekends.
• Less educated PCGs were more likely to report typically spending full day shifts (at least eight hours between 6 a.m. and 6 p.m.) during the week and on weekends providing care to CMC.

DISCUSSION

• Consistent with prior studies of related populations (e.g., children with technology dependence, children with developmental disabilities, children with cancer), a majority of these primary caregivers of CMC reported employment and income loss, and many reported negative career impacts that they attributed to the demands of caring for their CMC.
• Our findings suggest that the majority of the spouses/partners of these PCGs also experienced employment and income loss, many experienced negative career impacts, and 1 in 5 increased their work hours or took a more demanding, higher paid job due to the demands of family care for their child.
• The prevalence of employment and income loss suggests huge economic costs to families for providing home care to CMC.
• The investment of time by PCGs providing care for CMC is substantial and appears to be greatest for the least educated PCGs during daytime care shifts. This finding is consistent with the lower levels of employment among less educated PCGs in this study and among family caregivers more broadly.
• During evening and night care shifts, time spent providing care appears to be more evenly distributed across PCG education level.

CONCLUSIONS

• Lost employment is more than just that – it is compounded by foregone retirement contributions and results in great economic cost to families over time – even though the reason for lost employment is productive care work that the healthcare system relies upon.
• It is important to place these findings in the context of policies that affect all parents and family caregivers’ ability to maintain desired employment while ensuring high-quality care for their loved ones, including access to paid and unpaid leave, qualified respite care providers, and dependable child care.
• Clear understanding of the costs that families incur in the care of their CMC can guide efforts to assess whether current policies and programs are meeting their needs.
• In efforts to increase the efficiency of care for CMC, families should be considered part of the system of care, so that system-wide cost savings can be differentiated from transfers of institutional costs to families.

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