


Unpaid Caregiving: What are the Hidden Costs?

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The American Cancer Society estimates that approximately 62 000 people will be diagnosed with pancreatic cancer and nearly 50 000 will die from the disease in 2022 (1). Pancreatic cancer incidence is rising (2) and prognosis is poor, leading pancreatic cancer to eclipse breast cancer to become the third leading cause of cancer death in the United States (3). Further, it is projected to become the second leading cause of cancer death by 2026 (4). A treatment plan with pancreatectomy is the only hope of long-term survival. Stays in the hospital after pancreatectomy range from several days to weeks depending on the operation (pancreaticoduodenectomy vs distal pancreatectomy) and whether the operation was done in minimally invasive fashion vs open incision. Common side effects include diabetes and pancreatic exocrine insufficiency leading to daily enzyme replacement therapy (5–8) and often require intensive caregiving during the immediate postoperative recovery period, as well as during active treatment (chemotherapy and/or radiation), including transportation, accompaniment to appointments, and assistance in the home. For patients who need hospice care, an informal caregiver may be required for the remaining lifespan.

With 48 million adults serving as unpaid caregivers in the United States, the importance of understanding the challenges they face is essential (9). An estimated 6.1 million caregivers of people with cancer (10) are spending, on average, 33 hours per week caregiving (11). In addition to hours spent caregiving, half of these caregivers are employed and work an average of 35 hours per week (12). Reasons caregivers work include the absence of paid sick leave, need for income, provision of employer-sponsored health insurance coverage, and sustaining their career trajectory, which may be particularly important if their loved one has a poor prognosis, as is often the case with pancreatic cancer. The economic cost from informal caregiving in the United States is estimated at \$44 billion because of absenteeism and job loss (13). Additionally, the treatment cost of cancer is rising, making co-pays and out-of-pocket expenses a financial burden for patients and their families (14) and further increasing the need for a steady source of income.

Employed caregivers may experience reduced earnings from job loss, missed workdays, and/or changes to lower paying jobs

that will accommodate caregiving responsibilities (15). Like patients diagnosed with cancer, their caregivers may also experience trouble paying medical bills and distress about meeting financial obligations (16). Financial concerns can lead to poor quality of life and other life-altering decisions such as savings or retirement account withdrawals and home sale or refinancing—the consequences of which remain long after the patient is deceased (15). Not surprising, a decline in mental health is also associated with caregiving for adults diagnosed with cancer. High emotional stress from caregiving is reported by 50% of caregivers, and 43% report needing help managing emotional and physical stress (12). Because the mental and physical health of caregivers can be interdependent with that of the patient, patients may experience worse health outcomes when a caregiver is distressed (17).

In this issue of the Journal, Fong et al. (18) provide important insights into the experiences of informal caregivers of patients who received a pancreatectomy. The authors' focus on employed caregivers is an important contribution to the literature and our understanding of these caregivers' experiences. Nearly half (45%) of the informal caregivers were working for pay. These caregivers reported missing a median of 40 hours of work the month following the patient's surgery, which is close to the entirety of the annual allotment of paid sick leave for employees who have this benefit (19). This study also reported substantial reductions in work productivity and that employed female caregivers disproportionately experienced work-related consequences. Moreover, employed caregivers reported higher degrees of financial and emotional difficulty relative to similar caregivers who were not working. The authors note that this observation occurred despite "caring for younger patients, with greater medical literacy, and higher use of respite care" (18).

Why might employed informal caregivers experience additional mental health consequences relative to their nonemployed counterparts? Fong et al. (18) suggest that absence of paid sick leave and poor preparation for the caregiving role contribute to added stress. We expand on this list. The mean caregiver age was 53 years, and their patients were, on average, aged 63.8 years; both caregivers and patients were aged younger than

65 years, when they would become age eligible for Medicare benefits. Because they worked, these caregivers may not have qualified for lower income subsidies on the health insurance exchange market or for Medicaid. Thus, employment may have been their only source of affordable health insurance. Prior studies report that when employment is the only source of health insurance, not only do patients continue to work but they also work enough hours to meet or exceed the threshold to qualify for and maintain health insurance (20). This threshold is often at a level approaching full-time employment. Therefore, it is understandable how full-time work responsibilities combined with the pressure to maintain health insurance would be associated with mental health declines.

Younger caregivers may also be highly invested in their careers. Prior research reported that as the length of treatment increased and absenteeism rose, employed and insured women treated for breast cancer experienced greater mental health consequences (21). Likewise, caregivers may experience increased worry and concern for their careers given the extensive time away from work. Career concerns and job attachment may be especially important given that the 5-year survival for pancreatic cancer is only 5% to 10% (22). These caregivers may want to ensure that they have a job following the death of the patient. In addition, financial debt may continue long after the patient dies, further increasing the need for income from paid work (23).

Fong et al. (18) provide an insightful snapshot of caregiver burden following major surgery but underestimate the total financial burden of caring for patients with pancreatic cancer. The study was cross-sectional and assessed work status the week prior to when the caregiver answered the study survey, missing any employed caregivers who stopped working before surgery or shortly afterward. Only a single caregiver was surveyed; many patients with cancer have multiple unpaid caregivers. The study was also conducted in academic medical centers, where patients may be more affluent and had better outcomes associated with high-volume care. Future studies of caregivers should include longitudinal cohorts of more diverse patients, caregivers, and treating institutions with retrospective assessment of work prior to caregiving; data collection on the health insurance coverage for the patient, caregiver, and other dependents; percentage change in hours worked as the outcome rather than absolute hours worked; stratification of the cohort by gender in light of overwhelming evidence of differences between men and women in their labor supply and caregiving behavior (24,25); and to the extent possible, data on job characteristics such as paid sick leave, accommodations, and job tenure prior to the patient's diagnosis. Further information is needed on caregiver and patient characteristics including household income and earnings. These data provide important context to understanding the dynamics around informal caregiving and labor supply. Last, the control group selection could be improved by selecting caregivers who have more similar demographic characteristics to those who are working. Without more comparable control group participants, the results may be driven by unobservable characteristics (eg, financial need prior to caregiving) associated with employment status. Nonetheless, Fong et al. (18) provide the research and clinical community a launching point for future research.

Supports for employed caregivers are clearly needed. Fong et al. (18) advocate for paid sick leave and health insurance outside the employer. Additional supports include integration of caregivers in treatment plans via a separate electronic health record to screen, document, and address caregiver physical and mental health needs. If only 63% of cancer survivors discuss their

employment situation with the oncology care team (26), it is likely that even fewer caregivers discuss their employment situations with the oncology care team, leaving the caregiver and care team unaware of available supports. Research is needed to inform optimal delivery and coordination between the oncology care team and caregivers. In addition to physical and mental health and job screening, financial burden assessments are needed prior to and throughout the caregiving experience.

We add our endorsement of a national paid family and medical leave program. Paid sick leave will provide informal caregivers with financial protection along with job safety during their time away from work. Employer-sponsored health insurance continues to challenge patients and their caregivers who have no other source of health insurance. Policies such as further Medicaid expansions benefit low-income workers without employer-based health insurance options. Subsidies to improve affordability of coverage through marketplace exchanges outside employer-based mechanisms can support caregivers so that if job loss is unavoidable, health insurance coverage is available. In addition, worksite culture is not always supportive to caregiving. National policies coupled with a stronger business case are needed to support employed caregivers at the worksite. Our research and policy recommendations are summarized in Box 1. As we celebrate advancements in cancer screening and treatment, we must also be prepared to create policy and

Box 1. Summary of recommendations for understanding the economic burden to employed caregivers of patients diagnosed with cancer and the solutions needed

Recommendations

- Research
 - Data collection
 - Demographics on caregivers, patients, and dependents, including household income
 - Characteristics of health insurance coverage for family
 - Job characteristics and benefits
 - Study design
 - Inclusion of retrospective data collection prior to patient's diagnosis
 - Longitudinal cohorts of diverse caregivers, patients, and treating institutions
 - Control group of comparable nonemployed caregivers
 - Methods
 - Gender stratification in all analyses
 - Outcomes
 - Percent change in hours worked
 - Nonemployment
 - Reduced wages and earnings
 - Health insurance coverage disruptions or coverage status change
 - Financial impact hardship including increased debt and withdrawals from savings
 - Physical and mental health functioning
 - Incorporated assessment of caregiver employment and job requirements into treatment plan
- Practice
 - Paid sick leave
- Policy
 - Availability of health insurance coverage outside of employment
 - Medicaid expansion for low-income workers without employment-based health insurance options
 - Marketplace subsidies

practice changes that support survivors and their caregivers in the short and long term.

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