

Work-Related Impacts of Cancer Caregiving

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Individuals with cancer commonly rely on their informal caregivers (e.g., spouse/partner, family member, close friend) to help them manage the demands of the disease and its treatment. Caregiving, including helping with patient care, performing household chores, and providing emotional and practical support, can be particularly demanding for employed caregivers, who must juggle their work responsibilities while providing care. The work-related impacts of informal cancer caregiving that have been investigated in the literature include: (1) labor market withdrawal to provide care, (2) work modifications, (3) absenteeism, and, (4) presenteeism.

Keywords: caregivers ; cancer ; employment

1. Introduction

There are an estimated 53 million adults in the United States (U.S.) who are providing unpaid care and support to a spouse, partner, close family member, or friend with a chronic or serious health condition ^[1]. These informal caregivers have been described as a national resource because they provide a significant portion of outpatient care, reducing burden on the healthcare system ^[2]. Although the proportion of informal caregivers for individuals with cancer is estimated as 7–15% of the total caregiver population ^{[1][3]}, their experience is often characterized as distinct from those caring for individuals with dementia or other chronic conditions due to the abrupt onset and variable trajectory of the disease ^[4]. Informal cancer caregivers provide a broad range of essential services including assistance with activities of daily living, symptom management, social and emotional support, and advocacy (e.g., dealing with healthcare providers and insurance) ^{[5][6][7][8][9]}. Moreover, the growing reliance on outpatient care in oncology has resulted in informal caregivers performing increasingly complex care tasks—often with little training or support ^{[7][10]}. Thanks to advances in early detection and treatment, more individuals are also living longer after a cancer diagnosis ^[11]. As a result, there is a growing population of survivors who will spend their lives coping with the long-term and late effects of cancer and its treatment ^[12]. This extends the burden placed on informal caregivers ^{[13][14]}—half of whom are also employed ^[15]. It is estimated that cancer caregivers spend an average of 32.9 h per week providing care, with 32% providing >40 h of care per week, which is comparable to having a full-time job ^[16].

2. Costs of Care

Estimates suggest that informal caregiving accounts for 18–33% of the total cost of cancer care ^[17]. The economic value of the services caregivers provide has been calculated using different methods ^[18]. The opportunity cost method assesses the value of what caregivers give up when they provide care. This is usually based on the caregivers' lost wages, but it can also include estimates derived from other techniques (e.g., conjoint analysis, estimates of the monetary value of travel time or lost leisure time). The replacement cost (or proxy good) method assesses time spent on informal care through the labor market prices of a close market substitute (e.g., a housekeeper for housekeeping services, and a nurse for healthcare services).

One U.S. study that used the opportunity cost method to estimate the economic burden of localized prostate cancer found that the mean annual economic burden to caregiving partners was \$6063 (Range \$571–\$47,105) with the wide variation attributed to patient and caregiver characteristics ^[19]. A UK study using this method estimated the cost of informal care to cancer patients at end-of-life to be £948.86 per week, with social/emotional support and symptom management tasks representing the largest proportion of the monetary valuation ^[20].

Studies using the proxy good method have estimated the value of informal care as ranging widely from \$975 to \$19,112 per month (Mean = \$4809 per month, SD = \$6441) ^[18]. With regard to cancer type, lung cancer appears to have the highest cost of informal care (\$4784 per month), followed by ovarian cancer (\$4357 per month), with breast cancer caregivers incurring the lowest care cost (\$2523 per month) ^[21]. With regard to phase, two Irish studies compared the cost of informal care during the initial cancer diagnosis and treatment phases and found that cost was higher for the initial

diagnosis phase, suggesting that caregivers may have had to take more time off from work during this period (e.g., to take the patient for tests or second opinions) [22][23]. Overall, however, studies suggest that terminal cancer patients have the highest informal care costs [24][25].

Beyond this, cancer caregiving has been associated with out-of-pocket costs. Neglecting to account for out-of-pocket costs could lead to underestimation of the true cost of informal cancer caregiving as estimates suggest they make up 7–13% of total caregiver costs [22][24]. Types of out-of-pocket costs include insurance deductibles and co-pays for healthcare and medications, nutritional supplements and meals at the hospital, parking and travel costs for medical appointments, and formal help (e.g., professional care or paid domestic help) [26]. These costs range widely across studies (M = \$447 per month, SD = \$394, Range \$25–\$1233)—largely due to differences in the types of costs that are assessed and the phase/type of cancer that is examined [18].

3. Work-Related Impacts of Cancer Caregiving

The work-related impacts of informal cancer caregiving that have been investigated in the literature include: (1) labor market withdrawal to provide care, (2) work modifications, (3) absenteeism, and, (4) presenteeism. Each of these is described below.

3.1. Labor Market Withdrawal to Provide Care

In one of the few studies to examine the long-term employment outcomes of cancer caregivers, Veenstra et al. [27], surveyed 240 employed partners of women with early-stage breast cancer and found that 90% were still working four years after the patient's diagnosis. On the surface, this may appear to suggest that being a caregiver does not result in labor market withdrawal or losing one's job. Indeed, caregivers may be reluctant to quit their jobs in order to maintain their employer-based health insurance—particularly when they are the primary wage earners in the household [28]. Even when caregivers are secondary wage earners, their employment may take on greater importance if their patient (who was the primary wage earner) had to take a leave from the workforce while undergoing cancer treatment. Providing partial support for this idea, Hollenbeak et al. [29] found that the husbands of cancer survivors worked 1.5 more hours per week than the husbands of non-cancer survivors.

Nonetheless, it is important to note that the Veenstra et al. study [27] focused on spouses and partners of breast cancer patients. Breast cancer has a markedly favorable prognosis relative to most cancers and overwhelmingly affects women (many of whom have male partners). As such, findings may not be generalizable to other cancers or other types of caregivers (e.g., adult daughters, LGBTQ caregivers). Moreover, other studies suggest that a small number of caregivers (3–9%) do voluntarily quit their jobs, close their businesses, and pursue early retirement to devote more time and attention to their care recipients [15][26][30][31][32][33]. Unfortunately, the literature is unclear about whether caregivers who quit their jobs ever return to the labor market (e.g., after the patient dies or successfully completes cancer-directed treatment).

3.2. Work Modifications

Rather than exit the workforce entirely, 25–29% of caregivers make work modifications to satisfy their caregiving responsibilities [30][34]. These modifications include foregoing promotion or taking a less demanding job, changing from full- to part-time status, and changing work schedules (e.g., switching to the night shift, so they can take the care recipient to medical appointments) [15][34][35]. Estimates for work hour changes vary widely from 3 to 16 h per week [19][36]. Although some caregivers report taking on more work hours [30], most reduce their work hours, with the greatest reductions occurring during the terminal phase of the disease [27][31][32][36][37][38]. For some caregivers, a temporary reduction in work hours may precipitate the decision to change from full to part-time status [33][35].

Many caregivers take formal time off from work (paid or unpaid) to provide care. An analysis of 202 employed caregivers who were recruited from a population-based cohort of African American breast, colorectal, lung, and prostate cancer survivors found that more than half (52%) took paid time off from work to provide care, including 15% who took at least one month off [35]. However, in some workplaces, paid sick leave is uncommon and/or does not apply to the care of sick family members [34]. In addition, caregivers who have exhausted their allotted paid time off may have no recourse but to take unpaid time off. In fact, in that same population-based study, over a quarter of caregivers (27%) took unpaid time off, including 11% who took at least one month of unpaid time [35]. In the U.S., the Family and Medical Leave Act (FMLA) allows eligible employees to take up to 12 weeks of unpaid, protected leave annually for family and medical reasons with health insurance coverage continuation [39]. However, not all employees are covered under FMLA, and unpaid leave is financially undesirable for many.

3.3. Absenteeism

Absenteeism refers to any failure to report for or remain at work as scheduled, regardless of the reason. Studies from both the U.S. [15] and Canada [31] estimate that about half of employed caregivers come in late to work, leave work early, or take time off to accommodate their caregiving responsibilities. In fact, a large population-based study found that cancer caregivers are 1.75 times more likely to experience absenteeism relative to non-caregivers [40]. Reasons include transporting patients to medical appointments, caregiving activities and medical appointments taking longer than expected, and dealing with unanticipated issues related to patient care [30]. A U.S. study of 80 family caregivers of patients with primary malignant brain tumors found that one-third of employed caregivers experienced lost work hours due to providing care [41]. Although it is difficult to obtain precise estimates, studies have reported 11 lost work hours per week due to caregiving [42] to up to 7 days per month [43]. One study even estimated that cancer caregivers may lose as much as half of their workdays per month to assist with patient care [44].

3.4. Presenteeism

Presenteeism refers to reduced productivity while at work [45][46]. Overall productivity loss has been described as an “iceberg effect”, with the visible part of the iceberg representing absenteeism and the vast hidden area underneath as presenteeism [46]. Supporting this idea, a European study of lung cancer caregivers’ presenteeism, valued at \$8676 per year, had a larger impact on the overall cost of the work impact of providing lung cancer care than absenteeism (\$3234 per year) [47]. Population-based research suggests that cancer caregivers are 1.54 times more likely than non-caregivers to experience presenteeism [40], and the proportion of caregiver work productivity loss as a function of presenteeism has been estimated at 13–27% [42][48][49]. Studies have posited a variety of explanations including caregiver fatigue, worry, and time spent during the workday discussing patient care (e.g., with family, healthcare providers) [30], managing household responsibilities, and attending to patient medical needs (e.g., symptom management, transportation to medical appointments) [49][50]. Moreover, presenteeism may have downstream consequences for caregiver employment, with some caregivers reporting being overlooked for promotions due to their decreased availability [30], and others receiving warnings from their employers about their performance [15]. However, these long-term impacts are not fully understood.

3.5. Mental Health Impacts

While informal cancer caregiving is often an affordable and preferable alternative to paid caregiving, it can be an intensely burdensome and emotionally draining experience [7][31]. Cancer caregivers report a variety of mental health concerns including depression [51], social isolation [52], loss of self-identity [53], insomnia [54], and financial distress [55]. Over time, the caregiver’s mental health can wear on his/her physical health [56], adversely affect the patient’s mental health [57], and result in poor informal care quality [58]. Employed caregivers may also be a particularly vulnerable subgroup as over 64% report at least some difficulty balancing work and their caregiving responsibilities [35][59][60]. Studies have found that caregivers who are unable to complete work tasks experience greater job-related stress [30] and diminished perceptions of self-worth [61]. Caregivers with little or no flexibility in work hours also report greater stress than those with more flexible work arrangements [30].

With regard to depression, some studies describe higher levels of depressive symptoms among employed caregivers [62], whereas others have found no differences between employed and non-employed caregivers [49]. Still others have found that non-employed caregivers experience higher levels of burden than employed caregivers [15]. One explanation for this discrepancy is that even though balancing work and caregiving can be stressful, going to work affords a number of benefits including social support, respite, and economic security for caregivers [30][60][63][64]. It also provides a means for caregivers to preserve their individual identities (separate from the caregiving role) and foster a semblance of normalcy [61].

3.6. Vulnerable Caregivers

A variety of patient-related factors may increase likelihood of poor employment or mental health outcomes for informal cancer caregivers. For example, one study found that caregivers of colorectal (60%) and lung (54.2%) cancer patients reported more difficulty balancing work and caregiving than breast (34.4%) or prostate (29.5%) caregivers [35]. Caregivers of patients with newly diagnosed disease are more likely to report lost hours from work [34], and caregivers of patients who are undergoing chemotherapy or bone marrow transplant are more likely to take off work or make extended employment changes than caregivers of patients not undergoing these treatments [27][34][35]. Having a care recipient with advanced stage or terminal cancer, or more functional limitations, is associated with increased absenteeism [31][34][41][49], and having a care recipient in the terminal and palliative stages is associated with greater presenteeism [31]. With regard to sociodemographic factors, married/partnered caregivers are more likely to report absenteeism [35] and presenteeism [49]

than unmarried caregivers. Female caregivers are more likely to report feeling exhausted and fatigued relative to male caregivers, and Hispanic caregivers are less likely to be employed relative to non-Hispanic white caregivers [27]. In the context of health equity and cancer disparities, more research could be done to examine potential risk/resilience factors for employed caregiver outcomes. Characteristics such as different employee segments (e.g., hourly workers, contractors, full-time, etc.) or employer industry (e.g., service, industrial, professional, etc.), among other attributes may exert unmeasured influence on caregiver vulnerability.

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