Employment of Young Adult Cancer Caregivers, Other Disease Caregivers, and Non-Caregiving Adults

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Abstract: Young adults are increasingly taking on caregiving roles in the United States, and cancer caregivers often experience a greater burden than other caregivers. An unexpected caregiving role may disrupt caregiver employment, leading to lost earning potential and workforce re-entry challenges. We examined caregiving employment among young adult caregivers (i.e., family or friends) using the 2015 Behavioral Risk Factor Surveillance System (BRFSS), which included caregiving, employment, and sociodemographic variables. Respondents’ ages varied between 18 and 39, and they were categorized as non-caregivers (n = 16,009), other caregivers (n = 3512), and cancer caregivers (n = 325). Current employment was compared using Poisson regressions to estimate adjusted incidence rate ratios (aIRR) and 95% confidence intervals (95% CI), including gender-stratified models. We estimated employment by cancer caregiving intensity (low, moderate, high). Cancer caregivers at all other income levels were more likely to be employed than those earning below USD 20,000 (aIRR ranged: 1.88–2.10, all p < 0.015). Female cancer caregivers who were 25–29 (aIRR = 0.71, 95% CI = 0.51–1.00) and single (aIRR = 0.70, 95% CI = 0.52–0.95) were less likely to be employed than their counterparts. College-educated males were 19% less likely to be employed than high school-educated caregivers (95% CI = 0.68–0.98). Evaluating caregiver employment goals and personal financial situations may help identify those at risk for employment detriments, especially among females, those with lower educational attainment, and those earning below USD 20,000 annually.

Keywords: adolescent and young adult; cancer caregiver; employment; caregiver; caregiving intensity

1. Introduction

In the United States, there are 1.46 million cancer caregivers aged 18–34 [1]. Cancer caregiving is associated with greater caregiver burden (e.g., number caregiving hours, activities of daily living, instrumental activities of daily living) than caring for patients with other diseases [1]. Among other factors, caregiving burden influences cancer caregivers’ employment [2–4], and a quarter to a third take extended leave [3,4].

The number of working-age young adults engaged in caregiving continues to grow [1]. Young adults are increasingly taking on caregiving roles in the United States, and cancer caregivers often experience a greater burden than other caregivers. An unexpected caregiving role may disrupt caregiver employment, leading to lost earning potential and workforce re-entry challenges.
2. Materials and Methods

We used the 2015 Behavioral Risk Factor Surveillance System (BRFSS), a nationally representative computer-assisted survey of non-institutionalized adults in the United States that collects data on preventive health behaviors and risk factors [7]. The 2015 BRFSS is a publicly available combined telephone and landline survey, with a median response rate of 47.2%. The BRFSS and caregiver module are described elsewhere [8].

2.1. Participants and Outcome

There were 441,456 participants in the 2015 BRFSS; 24 states incorporated a 9-item caregiving module (n = 108,995). Of these, n = 20,187 were young adults aged 18–39. Caregivers were identified by the question “During the past 30 days, did you provide regular care or assistance to a family member who has a health problem or disability?” Cancer caregivers were identified by asking “What is the main health problem, long-term illness, or disability that the person you care for has?” We excluded respondents who were missing/refused for these questions. Our analytic sample included three mutually exclusive participant categories: n = 16,009 non-caregivers, n = 3512 other caregivers, and n = 325 cancer caregivers.

Our outcome was a binary variable indicating current employment for wages/self-employed versus unemployed/unable to work (including respondents who were out of work for one year or more, out of work for less than one year, and unable to work). Homemakers, students, and/or retirees were excluded from employment analyses (n = 3689).

2.2. Other Measures

Sociodemographic variables included age, gender, race/ethnicity, marital status, and education. The caregiving intensity composite assigns points for managing personal care (e.g., giving medications, feeding, dressing, bathing), household care (e.g., cleaning, finances, meals), and hours of care provided per week [1,9]. Points are summed (0–8 points) based on personal care (+3 points), household care (+3), personal care and household care (+4), and the number of hours per week engaged in caregiving (+1–4 assigned to the following categories 0–8, 9–19, 20–39, and ≥40 h) [9]. We categorized intensity as low (1–4 points), moderate (5 points), and high (6–8 points) [9].

2.3. Statistical Analysis

Complex survey weighting procedures were incorporated into all analyses. Descriptive statistics were calculated using raw counts and BRFSS weight-adjusted proportions. Sociodemographic factors were compared between cancer caregivers and non-caregivers using Pearson \( \chi^2 \) tests, and then between caregivers of other conditions and cancer caregivers. We estimated crude incidence rate ratios (IRR) and adjusted incidence rate ratios (aIRR) and 95% confidence intervals (95% CI) using survey-weighted Poisson regression models with robust standard errors for common outcomes [10]. We compared the employment of non-caregivers to other caregivers and cancer caregivers. Among cancer caregivers, we estimated models of employment by caregiving intensity, age, gender, race/ethnicity, marital status, education, and annual household income, and ran adjusted models stratified by gender. All data were analyzed using Stata 16.

3. Results

Cancer caregivers were less likely to be unemployed/unable to work than other caregivers (14.1% vs. 20.3%, Table 1). More cancer caregivers were older (18–24 years: 32.0% vs. 29.7%, 25–29 years: 22.2% vs. 19.2%, \( p < 0.001 \)) than Other caregivers, but younger than non-caregivers (\( p < 0.001 \)). Cancer caregivers tended to have lower incomes than non-caregivers (\( p = 0.036 \)). Compared to cancer caregivers, other caregivers differed by age, education, and income (all \( p < 0.01 \)).
Table 1. Sociodemographic factors for young adult cancer caregivers, non-caregivers, and other caregivers.

| Employment status       | Cancer Caregivers | Non-Caregivers | Other Caregivers |
|-------------------------|-------------------|----------------|------------------|
|                         | N | % 1   | N | % 1   | p-Value 2 | N | % 1 | p-Value 3 |
| **Employment status**   |   |       |   |       |           |   |       |           |
| Employed for wages/ self-employed | 230 | 85.9 | 11,462 | 85.9 | 0.990 | 2517 | 79.7 | <0.001 |
| Unemployed/unable to work | 43 | 14.1 | 1659 | 14.1 |          | 572 | 20.3 |          |
| Out of work for 1 year or more 5 | 14 | 32.0 | 165 | 29.3 | 0.222 | 168 | 29.4 | 0.562 |
| Out of work for less than 1 year 5 | 12 | 14.1 | 430 | 29.3 |          | 165 | 29.4 |          |
| Unable to work 5   | 17 | 10.0 | 610 | 30.5 |          | 179 | 28.1 |          |
| **Age**              |   |       |   |       |           |   |       |           |
| 18–24                  | 43 | 57.0 | 7687 | 94.4 | 0.138 | 1750 | 46.6 | 0.463 |
| 25–29                  | 72 | 22.8 | 4142 | 26.3 |          | 510 | 25.6 |          |
| 30–34                  | 86 | 26.3 | 4082 | 24.1 |          | 828 | 24.1 |          |
| 35–39                  | 93 | 19.4 | 4650 | 21.7 |          | 957 | 24.7 |          |
| **Gender**            |   |       |   |       |           |   |       |           |
| Female                 | 126 | 56.4 | 7687 | 94.4 |          | 1750 | 46.6 |          |
| Male                   | 199 | 43.6 | 9138 | 50.6 |          | 1339 | 51.4 |          |
| **Race/ethnicity**    |   |       |   |       |           |   |       |           |
| Non-Hispanic White     | 212 | 67.1 | 11,220 | 65.0 | 0.642 | 1950 | 64.4 | 0.583 |
| Other                  | 110 | 32.9 | 5412 | 35.0 |          | 1092 | 35.6 |          |
| **Marital status**    |   |       |   |       |           |   |       |           |
| Married/Partnered      | 149 | 41.7 | 8024 | 43.0 | 0.766 | 1357 | 41.6 | 0.263 |
| Unmarried              | 176 | 58.3 | 8733 | 57.0 |          | 1724 | 58.4 |          |
| **Education** 4        |   |       |   |       |           |   |       |           |
| ≤ High school graduate | 119 | 46.0 | 5766 | 42.2 | 0.675 | 1139 | 46.7 | 0.001 |
| Some college/technical | 102 | 31.2 | 5073 | 33.4 |          | 1080 | 34.5 |          |
| ≥ College graduate     | 104 | 22.9 | 5958 | 24.4 |          | 866 | 21.8 |          |
| **Annual household income (USD)** |   |       |   |       |           |   |       |           |
| Less than $20,000      | 57 | 15.6 | 2472 | 18.2 | 0.036 | 583 | 22.1 | <0.001 |
| $20,000 to $34,999     | 66 | 22.8 | 2848 | 20.6 |          | 644 | 25.0 |          |
| $35,000 to $49,999     | 53 | 23.4 | 2196 | 15.1 |          | 384 | 14.2 |          |
| $50,000 to $74,999     | 29 | 8.5  | 2337 | 15.4 |          | 397 | 14.9 |          |
| $75,000 or more        | 75 | 29.7 | 4423 | 30.7 |          | 635 | 23.7 |          |
| **Caregiving intensity** |   |       |   |       |           |   |       |           |
| Managing personal care | Yes | 196 | 57.8 | - | - | 1689 | 53.6 | 0.149 |
| No                     | 128 | 42.2 | - | - |          | 1357 | 46.4 |          |
| Managing household care| Yes | 274 | 84.5 | - | - | 2495 | 81.9 | 0.238 |
| No                     | 50 | 15.5 | - | - |          | 553 | 18.1 |          |
| Hours of care provided per week |   |       |   |       |           |   |       |           |
| Up to 8 h            | 188 | 57.8 | - | - |          | 1810 | 60.1 | 0.782 |
| 9–19 h               | 49 | 15.1 | - | - |          | 417 | 14.6 |          |
| 20–39 h              | 41 | 10.1 | - | - |          | 295 | 10.2 |          |
| 40 h or more        | 35 | 17.0 | - | - |          | 445 | 15.1 |          |
| **Caregiving Intensity Composite** |   |       |   |       |           |   |       |           |
| Low                   | 108 | 40.8 | - | - |          | 1184 | 45.8 | 0.479 |
| Moderate              | 83 | 30.2 | - | - |          | 681 | 24.4 |          |
| High                  | 86 | 29.0 | - | - |          | 772 | 29.8 |          |

1 Weighted for BRFSS sampling. 2 Weighted chi-square test of independence comparing cancer caregivers to non-caregivers, bold indicates significance at p < 0.05. 3 Weighted chi-square test of independence comparing cancer caregivers to other caregivers, bold indicates significance at p < 0.05. 4 Education missing for n = 28 non-caregivers and n = 4 non-cancer caregivers. 5 Weighted proportions represent only those who were unemployed. 6 Totals do not equal column headers because homemakers, students, and/or retirees were excluded from employment analyses (n = 3689).

Cancer caregivers’ employment did not differ significantly from non-caregivers or other caregivers; however, other caregivers were less likely to be employed than non-caregivers (IRR = 0.91, 95% CI = 0.89–0.94, p < 0.001), even after adjusting for age, gender, race/ethnicity, marital status, education, and annual household income (aIRR = 0.94%, CI = 0.91–0.97, p < 0.001, data not shown).

Among cancer caregivers, only income influenced the overall likelihood of employment, with caregivers from all income groups having higher likelihood of employment compared to those earning less than USD 20,000 annually (aIRR ranged: 1.88–2.10, all p ≤ 0.015, Table 2). However, female caregivers aged 25–29 were less likely than those aged...
18–24 years to be employed (aIRR: 0.71, 95% CI = 0.51–1.00). Single female cancer caregivers were less likely to be employed than married/partnered female cancer caregivers (aIRR = 0.70, 95% CI = 0.52–0.95), and female cancer caregivers in all but the highest income bracket were more likely to be employed than those earning below USD 20,000 annually (all \( p \leq 0.047 \)). Among males, those with the highest educational attainment were significantly less likely to be employed (aIRR: 0.81, 95% CI 0.68–0.98) than the least educated. All models adjusted for age, race/ethnicity, marital status, education, and annual household income, and the overall model was also adjusted for gender.

### Table 2. Factors associated with employment among all young adult cancer caregivers and by gender.

| Caregiving intensity | Full Sample 1 | Gender-Stratified Models | Male 2 |
|----------------------|---------------|--------------------------|--------|
|                      | aIRR | 95% CI | p-Value | % | aIRR | 95% CI | p-Value | % | aIRR | 95% CI | p-Value |
| Low                  | Ref. | Ref. | 37.1 | Ref. | 45.3 | Ref. | 39.8 | Ref. | - | - | - |
| Moderate             | 0.95 | 0.86–1.06 | 0.374 | 26.5 | 0.88 | 0.71–1.08 | 0.218 | 34.7 | 0.98 | 0.87–1.11 | 0.796 |
| High                 | 0.84 | 0.70–1.00 | 0.056 | 36.3 | 0.74 | 0.55–1.00 | 0.054 | 20.1 | 0.97 | 0.83–1.14 | 0.734 |
| Age                  | Ref. | Ref. | 26.2 | Ref. | 39.8 | Ref. | - | - | - | - |
| 18–24                | 0.89 | 0.69–1.16 | 0.408 | 24.3 | 0.71 | 0.51–1.00 | 0.049 | 19.3 | 1.21 | 0.98–1.50 | 0.069 |
| 25–29                | 1.12 | 0.97–1.29 | 0.107 | 28.5 | 1.21 | 0.92–1.59 | 0.182 | 23.5 | 1.11 | 0.92–1.35 | 0.265 |
| 30–34                | 0.99 | 0.85–1.14 | 0.854 | 21.0 | 1.04 | 0.77–1.42 | 0.775 | 17.4 | 1.07 | 0.86–1.34 | 0.531 |
| 35–39                | 1.21 | 0.98–1.50 | 0.069 | 19.3 | 1.21 | 0.92–1.59 | 0.182 | 23.5 | 1.11 | 0.92–1.35 | 0.265 |
| Gender               | Ref. | Ref. | 0.99 | 0.89–1.11 | 0.834 | - | - | - | - | - |
| Male                 | 1.02 | 0.89–1.18 | 0.729 | 32.2 | 0.97 | 0.75–1.24 | 0.797 | 31.2 | 1.12 | 0.97–1.30 | 0.112 |
| Non-Hispanic white   | Ref. | Ref. | 67.8 | Ref. | 68.8 | Ref. | - | - | - | - |
| Other                | 1.02 | 0.89–1.18 | 0.729 | 32.2 | 0.97 | 0.75–1.24 | 0.797 | 31.2 | 1.12 | 0.97–1.30 | 0.112 |
| Marital status       | Ref. | Ref. | 49.6 | Ref. | 35.7 | Ref. | - | - | - | - |
| Married/partnered    | 0.89 | 0.78–1.02 | 0.101 | 50.4 | 0.70 | 0.52–0.95 | 0.020 | 64.3 | 0.97 | 0.86–1.10 | 0.681 |
| Education            | Ref. | Ref. | 38.7 | Ref. | 55.5 | Ref. | - | - | - | - |
| <High school         | 0.92 | 0.78–1.09 | 0.334 | 31.5 | 0.99 | 0.72–1.37 | 0.962 | 30.7 | 0.92 | 0.80–1.06 | 0.235 |
| Some college         | 1.03 | 0.86–1.23 | 0.74 | 29.8 | 1.18 | 0.92–1.53 | 0.195 | 13.8 | 0.81 | 0.68–0.98 | 0.028 |
| College graduate     | 1.21 | 1.13–1.29 | 0.010 | 32.1 | 1.69 | 0.99–2.98 | 0.054 | 26.7 | 2.16 | 0.79–5.89 | 0.133 |

1 Adjusted for age, gender, race/ethnicity, marital status, education, and annual household income. BRFSS weights applied. Bold indicates significance at \( p < 0.05 \).

2 Adjusted for age, race/ethnicity, marital status, education, and household income. BRFSS weights applied.

3 Intensity missing/refused for \( n = 3 \).

### 4. Discussion

In this nationally representative sample, young adult caregivers were less likely to be employed than non-caregivers. Female young adult cancer caregivers who were single, aged 25–29 years, and those in households earning below USD 20,000 had lower likelihood of employment, as did males with the highest educational attainment. Sociocultural expectations for females to become caregivers may, in part, explain these differences. Caregiving that interferes with employment inflicts long-term detriments on caregivers’ careers and emotional wellbeing [4], and these effects may be pronounced for young adults and female cancer caregivers. As young adults increasingly engage in informal caregiving, supporting caregiver employment, a major component of economic stability, is a public health priority [11].

At a young age, women who leave the workforce to provide care may experience difficulty returning to work (e.g., lost or outdated skills, scheduling conflicts, overdue licensure), potentially impacting their financial stability. In our sample, single women, women from low-earning households, and those aged 25–29 were especially likely to be unemployed. Female cancer caregivers earning between USD 20,000 to USD <75,000 were more likely to be employed than the lowest earning caregivers, underscoring the need for flexible employment options that are not tied to educational attainment for these caregivers. Male cancer caregivers with the highest educational attainment were significantly less
likely to be employed compared to those with high school education. High caregiving intensity had a significantly negative effect on employment among caregivers, but this was attenuated after adjusting for income (data not shown), potentially suggesting that higher earning caregivers have access to resources that mitigate the influence of high-intensity caregiving on employment that lower earning caregivers do not. Cumulative employment impacts resulting from lack of flexible work schedules, family leave, and paid time off for caregiving may restrict young cancer caregivers’ workforce retention [12,13].

The BRFSS does not consider preferences for full versus part-time work, the toll of working while caregiving (i.e., presenteeism), nor caregivers’ desires for workforce participation. Hispanic and African American caregivers disproportionately report financial and employment burdens, this sample may underrepresent their employment impacts, but this is a critical area for future study.

5. Conclusions

Federal policies and certain state policies provide limited employment accommodations for young caregivers. More robust support is needed to mitigate the negative effect of caregiving on young adults’ employment, especially for single females and those from low-earning households. Policies that support high-quality employer flexibility and educational attainment may protect young adult caregivers from negative employment changes, especially for female young adult cancer caregivers.

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