Impact of Cancer on Economic Status Among Survivors and Their Families

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Over 10 million of American adults are cancer survivors (Ries, Melbert et al. 2008). Every year, an additional 1.5 million are diagnosed with cancer, with nearly two thirds surviving 5 years after the diagnosis (Jemal, Siegel et al. 2009). The national burden of cancer in terms of health and longevity has been well documented (Brown, Lipscomb et al. 2001). The economic burden, at the national level, has also been described, with total cost exceeding $100 billion annually (Brown and Fintor 1995; Brown, Lipscomb et al. 2001). About 30% of this amount comprises direct costs such as hospital care and medications, while 10% is due to morbidity and 60% to mortality costs.

At the individual level, research has shown that adult cancer survivors report difficulties in multiple domains. Many have psychosocial adjustment problems, including depression, fears and anxieties about their illness and about their functioning in the family and society (Hewitt, Rowland et al. 2003; Baker, Denniston et al. 2005).

In contrast, relatively little is known about the *economic* outcomes among the survivors, and even less about the effects on the survivors' families. This is an important omission -- the disease impacts the entire family, not just the patient. For instance, the spouse of the patient may discontinue employment to provide care, the family may lose a portion of their income and/or savings (Covinsky, Goldman et al. 1994). This paper examines the impact of a cancer diagnosis on the employment, earnings, expenditures, and wealth of adults living with a history of cancer and their families.

A diagnosis of cancer and subsequent medical interventions may have economic impacts in multiple ways. The patient may need to discontinue employment or work fewer hours due to the side effects of the treatment or disability. Unfortunately, studies of the fiscal impact of cancer or other health conditions on income have been conducted mostly with near-retirement age and retired adults, and focused more broadly on major health conditions, not just cancer. Studying a population of married older adults, Wu (2003) found no effect of several health conditions including cancer on incomes of married couples. In contrast, Smith (2003), using the same data, found major health events associated with a 30% decline in income. Elsewhere, Smith (Smith 1999) calculated the reduction in employed older adults' earnings of around $2600

following the onset of a severe condition, although the income of other household members remained unaffected.

There is great variation in the impact of the disease on the economic well-being of the afflicted families. Focusing broadly on serious illnesses, families with younger, more disabled, and lower-income patients were more likely to report loss of employment, income and savings (Covinsky, Goldman et al. 1994; Smith 2003). A recent review of studies on financial stress among terminally ill cancer patients found a high proportion of families with economic distress, with up to a third depleting most or all savings (Hanratty, Holland et al. 2007).

This project contributes to the literature on economic well-being of cancer survivors in multiple ways. Existing studies typically employ one of two data sources. The first group uses non-representative samples of cancer patients often found through cancer registries, sometimes focusing specifically on terminal patients or, in contrast, long-term survivors. These studies rarely have detailed information about the economic circumstances of cancer patients prior to diagnosis. The second group of studies has used nationally representative data of older American adults, such as AHEAD or the HRS. The economic status of the elderly, however, is likely to be affected by cancer differently, since the survivors are no longer in labor force and their income is not tied directly to their ability to continue working. Moreover, these studies have typically analyzed a broad group of health conditions including, but not limited to, cancer.

In contrast, our project is based on a long-term prospective survey of a nationally-representative sample of adults across the full age range, with detailed income and earnings information available before and after the diagnosis, allowing for a broader generalization to the U.S. adult population. Studying the working-age population is important because the cancer diagnosis can influence the capacity for employment and hence generating income, both short-term and long-term. Additionally, our study uses detailed income data for all family members collected in the PSID, considered the benchmark survey for analysis of economic status of individuals and families.

There are two primary objectives of the study. First, we estimate the impact of a cancer diagnosis on future earnings and total family income. Second, we examine the variation in the effects across individuals and families, identifying demographic and socioeconomic factors associated with a particularly severe economic burden of cancer.

DATA AND METHODS

Data source

Analyses are based on data from the Panel Study of Income Dynamics (PSID), conducted by the Survey Research Center at the University of Michigan. The PSID began in 1968 as a longitudinal study of a representative sample of US individuals and the family units in which they reside. Starting with a national sample of 18,230 people living in 4,800 families in 1968, the PSID has re-interviewed individuals from those families every year (biennially starting in 1997) since that time, whether or not they are living in the same dwelling or with the same people. In addition, all people born to or adopted by PSID sample members become sample numbers themselves and are followed in subsequent waves, with over 9000 families currently followed. This design feature replenishes the sample with new birth cohorts. Annual response rates have been 96%-98% for the core PSID families in almost every wave, and 50-65% of individuals who were non-response at some point came back to the study in a subsequent wave. Information is collected biannually in telephone interviews lasting about 75 minutes.

In 1999, PSID added a battery of questions about selected health conditions, including cancer, to the core items collected at every wave. Details of the survey design have been published elsewhere (Hill 1992). All data and documentation are available at http://psidonline.isr.umich.edu/. Data quality reports (Kim and Stafford 2000; Andreski, Gouskova et al. 2005; Wilhelm 2006; Gouskova and Schoeni 2007) are available as well, including evaluation of the self-reported health information that shows low item nonresponse and close alignment of estimates of smoking, health insurance coverage, obesity, and chronic conditions in comparison with the National Health Interview Survey (Andreski, Gouskova et al. 2005; Smith 2007; Smith 2009).

Sample

Questions regarding health conditions were asked at every wave since 1999 with respect to the two primary adults heading each family unit, referred to as "heads" and "wives." The analysis sample thus includes all heads and wives aged 18 and above between 1999 to 2005.[1]

[1] The most current PSID wave is from 2007; this version of the paper incorporates cancer data through 2005 and income data through 2007. The final version will also add cancer information collected in 2007.

Measures

Cancer occurrence and timing. In all four waves since 1999, respondents were asked: "Has a doctor ever told you that you have or had cancer or a malignant tumor?" A positive response was followed by a short series of related items, including the time of onset. In 1999, 2001, and 2003, respondents were asked: "How long have you had this condition?" In 2005, the question was changed to "How old were you when you were first diagnosed with cancer?" If respondents indicated a different year of diagnosis during the multiple interviews, we used the information from the earliest wave under the assumption that the reply closest in time to the diagnosis would likely to be more precise than later replies. Timing imprecision is defined in terms of variation among the repeated reports of the year when the cancer was first diagnosed. We operationalize imprecision as the absolute difference between the maximum and minimum reported year of diagnosis. The variable is used as an ordered categorical covariate, coded as 0, 1, 2-3, and 4+ years of difference.

Additional cancer-related variables. Two additional characteristics related to the cancer diagnosis are used in the analyses: activity limitations due to cancer and primary cancer site. At all four waves from 1999 to 2005, the follow-up after a positive cancer report included the question "How much does this condition limit your normal daily activities?" The 4-point scale ranged from "not at all" to "a lot." We coded the variable as 1 if respondent mentioned "a lot" or "somewhat" degree of limitations at any wave and 0 otherwise. In 2005, the survey asked for the first time about the type of tumor: "What type of cancer (do/did) you have? In what part of your body [is/was] it?" The cancer sites included breast, colon, lung, lymphoma or leukemia, melanoma, prostate, skin (not further specified), uterine, ovarian, cervical, and other. Respondents could report one or more cancer sites; however, over 99.5% of cancer survivors reported only one type of cancer. For the 20 individuals who mentioned a second cancer site, we use the first-mentioned type.

Socio-demographic variables. Year of birth is calculated from age at the time of interview. Gender is coded 0=male, 1=female. Race/ethnicity is coded 0=non-Hispanic white, 1=black, Hispanic, and other. Education is reported as the highest year of schooling completed, with a range from 1 to 17 years. Marital status is defined as married or cohabiting=0, and not married=1 if respondents were divorced, widowed, or single at any wave. Rural/urban residence (urban as reference) is dichotomous, coded as rural if the respondent resided in small

non-metropolitan area or a rural area at any wave. Census region was based on 1999 information and categorized as Northeast (reference), Midwest, South, and West. Finally, reports by proxies have previously been found less reliable than self-reports (Guyatt, Feeny et al. 1993; Smith 2007). For each respondent, we generated a 'self/proxy' variable, coded as 'only self' if all available data were self-reported, 'only proxy' if all data were reported by proxies, and 'both self and proxy reports' for all other cases.

Income. Total family income is the sum of taxable, transfer, and social security incomes of the head, wife, and other family members. Income is adjusted for inflation to 2000 dollars using the CPI. Wages refer to the income component generated directly by participating in the labor force, and hence most directly influenced by the need to discontinue work due to illness.

Gender, race, and educational attainment are assumed to be time-invariant predictors. In the preliminary analysis stage, marital status and region of residence are also treated as time-invariant controls. Age is included in all models as a time-varying predictor. These demographic covariates were collected at each wave with no or few missing variables.

ANALYTIC APPROACH

We use fixed-effect model approach developed by Jacobson, LaLonde, and Sullivan (1993) for examining the earnings declines of displaced workers. The time-specific earnings of workers y_{it} were modeled as a function of a set of dummy indicators I_{it}^{p} that code each period before, at, and after displacement:

$$\mathrm{y_{it}} = \alpha_{\mathrm{i}} + \mathrm{x_{it}}\beta + \sum \mathrm{I_{it}^{p}}\delta_{\mathrm{p}} + \varepsilon_{\mathrm{it}}. \quad (1)$$

In our analysis, $\mathrm{y_{it}}$ is the specific economic indicator (such as log-wages) for individual i at time period t, where t is in years ranging from 1989 to 2004. The α_{i} is the within-individual intercept, $\mathrm{x_{it}}$ is age (and, optionally, other time-varying control variables), and $\mathrm{I_{it}^{p}}$ is an indicator of the year since diagnosis where $p = 0$ is the year of diagnosis. We restrict the model to a maximum of 5 years around the diagnosis, $-5 \leq p \leq 5$. The effect δ_{p} of each period around the diagnosis year is expected to be zero for $p < 0$ and negative for $p \geq 0$ -- that is, we would expect no effect of cancer on economic indicator prior to the diagnosis, and a significant effect in the year of diagnosis and afterwards. Employment in each period is modeled similarly, using logistic fixed-effects models with equivalence set of predictors as in (1). Some analyses are stratified by age or other predictors.

The JLS approach is ideal for a detailed modeling of the time-specific outcomes unconstrained by an a priori functional form for the changes in income and employment post-diagnosis. However, we also used a more parsimonious specification of the time dummies, similar to Reville and Schoeni's (2001) approach where the time periods dummies are for longer periods. One of the specifications used here is 'short-term' dummy, which equals 1 for $0 \leq p \leq 2$ and zero otherwise, 'mid-term' dummy, which equals 1 for $2 \leq p \leq 5$ and zero otherwise, and 'long-term' dummy that is 1 for $p > 5$ and zero otherwise. This approach allows easier incorporation of interaction terms. We present models where the post-diagnosis dummies are interacted with age, gender, and marital status. Analyses are conducted using Stata 10.0 (2007, StataCorp, College Station, TX).

Additional analytic issues, to be resolved in Fall 2010, include the following. The current results are unweighted so we will conduct sensitivity analyses to determine the robustness of the findings using sampling weights. We will carefully consider how to treat comorbidities for cancer patients and other severe health conditions for individuals without cancer, in order to isolate the effects of cancer as opposed to other major conditions. We will consider alternative analytic approaches, including the Arellano-Bond estimator (Arellano and Bond 1991), recently used in an analysis of income and health in the PSID data (Halliday 2007), and growth curve models (Muthén 2002; Chou, Yang et al. 2004). We will also incorporate information on survival of the respondents with history of cancer.

PRELIMINARY RESULTS

Sample descriptives

Among the 14,766 survey respondents who were heads of household or wives during at least one the 1999, 2001, 2003, or 2005 survey waves, 6.6% (N=978) reported having been diagnosed with cancer during at least one survey wave. The characteristics of this group, compared to those reporting no cancer diagnosis, are shown in table 1 as unweighted statistics at the first wave when cancer information was collected, 1999. We also show the most recent income and wealth information, from 2004 and 2005 respectively. The individuals with cancer are significantly older that those who did not report cancer, 54 vs. 40 years. About 65% of the cancer patients are women, and about a quarter are non-white. There are some differences between the respondents who reported cancer and those who did not in marital status, place of residence, and socioeconomic status as measured by education, income, and wealth –

however, those differences are not significant when we take into account the higher average age of the cancer group. There is a substantial difference in the employment rate between the persons who did not report cancer versus those who did, 72% vs. 47%. This difference is not due to the age difference between these two groups. However, some of the cancer survivors had cancer prior to 1999, which may have influenced their 1999 employment. When we exclude those who had cancer in or prior to year 2000, the employment difference becomes not significant (data not shown).

The group of individuals who reported a cancer diagnosis is heterogeneous with respect to the type of cancer and the extent of limitations to activities of daily living due to the disease. Table 2 summarizes the distribution of these two variables. The data are based on the 2005 wave because cancer type information was not collected in the prior surveys. The modal cancer type is lung cancer, followed by breast cancer. These do not correspond to the major cancer types among survivors in the US population where the two modal sites are breast cancer and prostate cancer, suggesting misreporting, or more specifically underreporting of prostate cancer and overreporting of lung cancer. Most cancer survivors (75%) report no limitations as a result of their condition, and additional 9% report 'just a little' limitation.

Effect of cancer on total family income

Figure 1 shows results from FE models of the effects of each year pre- and post-diagnosis on total family income in the aggregate sample. There is some suggestion of a dip in income the first year after diagnosis, followed by a partial return. These trends, however, are only suggestive – the effects of the individual time periods are not significantly different from zero.

The second figure isolates only taxable income, the bulk of which comes from wages and is thus more directly linked to leaving labor force or cutting work hours due to illness. The impact of a cancer diagnosis here is significant over the 5-year period following the diagnosis. The decline in taxable income begins one year prior to the diagnosis, which can be an artifact of imprecise reporting of the timing of the diagnosis, or perhaps reflects health problems due to cancer before it's diagnosed. The drop in taxable income is largest in the first year after the diagnosis -- nearly 17% drop over what would be expected in the absence of cancer.

The incomes of retired individuals, who are most likely to have been diagnosed with cancer, are less likely to be impacted by the illness than the employment and other taxable incomes of working-age adults. Figure 3 therefore shows results from the models stratified by three age groups: 18-29, 30-64, and 65+. The plot indicates that the total income of families with a retirement-age cancer survivor remain relatively flat after the diagnosis. There is a more pronounced dip in family incomes for the older working-age survivors during the first post-diagnosis year, followed by a return to the non-diagnosis levels. The youngest group shows a much steeper fall throughout the post-diagnosis period, suggesting a long-term negative effect of cancer on economic well-being. However, the downward trend begins well before the diagnosis year. This could be due to misreporting of the time at diagnosis or it could suggest that the observed downward income trajectory is not caused by the illness but other factors.

SUMMARY AND NEXT STEPS

With improved diagnosis and treatment, about two thirds of cancer patients now survive more than 5 years. As cancer increasingly changes from a terminal illness to a chronic disease, the understanding of how its diagnosis and treatment affect the economic well-being of adult patients and their families gains importance. This project focused on the impact of cancer diagnosis of employment of cancer survivors and their family income.

Using a fixed-effects approach used by Jacobson, LaLonde, and Sullivan (1993) and modifications introduced by Reville and Schoeni (2001), we found significant effects of cancer on total family income and taxable family income.

The next step of this project will be to disaggregate the income variable further to examine its individual components, and to focus on own and spousal indicators separately. In addition, we plan to explore the impact of cancer on medical expenditures, which are available in the PSID starting in 1999. Finally, we intend to analyze changes in wealth, which may be more pertinent to the economic well-being among older adults and elderly than income.

Table 1. Characteristics of the sample (PSID, 1989-2007)

	Cancer	No cancer	Difference[1]
Year of birth	1947	1961	.00
Female (%)	61.4%	53.1%	.00
Nonwhite (%)	27.4%	40.3%	.00
Not married in 1999 (%)	30.7%	32.9%	.26
Rural in 1999[3] (%)	16.4%	13.9	.08
South in 1999 (%)	41.4%	43.9%	.21
Education, in years	12.8	13.0	.09
Income[2] in 1988 (median)	$48,530	$48,222	.85
Income in 2006 (median)	$41,934	$49,099	.00
Taxable inc., 1988 (median)	$37,172	$41,464	.11
Taxable inc., 2006 (med)	$24,650	$40,800	.00
N	639	13,788	---

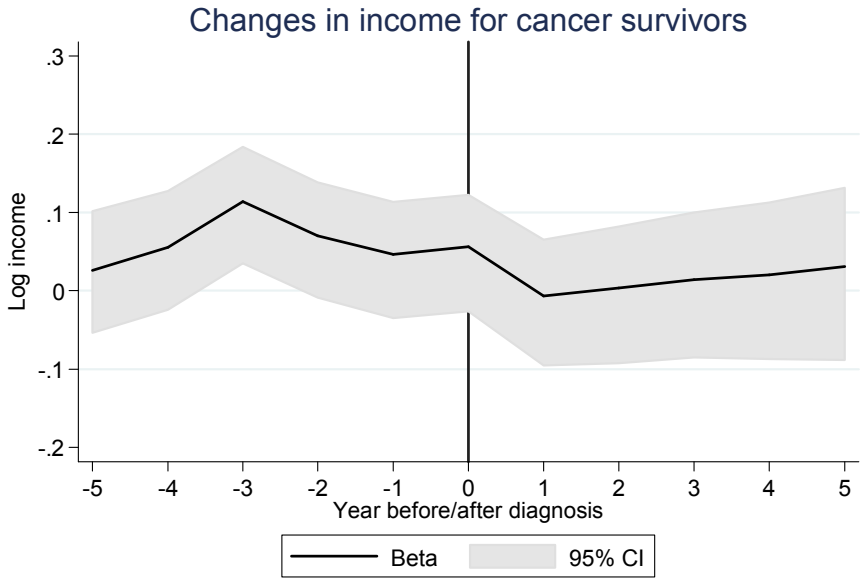
Note: unweighted means, medians, and proportions. The total sample, a sum of 'cancer' and 'no-cancer' groups, includes all individuals who were heads or wives during one or more waves where cancer questions were asked, i.e. 1999 to 2005. Respondents who indicated cancer but had either 1) no valid year of diagnosis, 2) discrepancy among years of diagnosis reported at different interviews of more than 5 years, or 3) reported a non-melanoma skin cancer in 2005 were excluded from analyses.

[1]This column shows the p-value from the tests of difference between the 'cancer' and 'no-cancer' groups in each variable, conditional on age -- independent samples t-test for means, nonparametric K-sample test for medians, and chi-square tests for proportions.

[2]All income variables are inflation-adjusted to 2000 dollars. The income questions refer to the year prior to each interview wave.

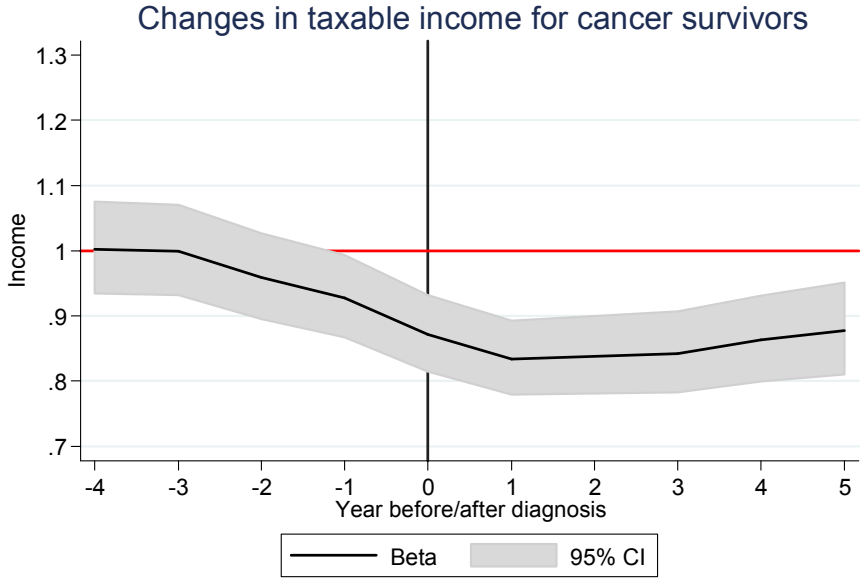
[3]The 'rural' variable is coded 0 for those in urban metropolitan areas with population of 20,000 or more, and 1 for those in small urban areas with population less than 20,000 or completely rural areas.

Figure 1.



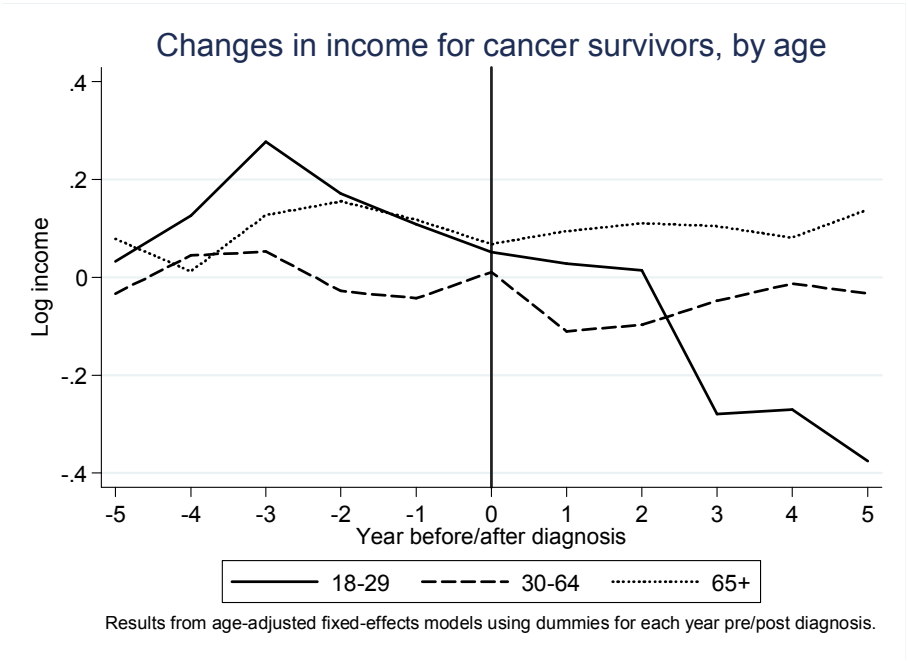
Results from age-adjusted fixed-effects models using dummies for each year pre/post diagnosis.

Figure 2.



Results from age-adjusted FIXED-effects models using dummies for each year pre/post diagnosis.

Figure 3.


Changes in income for cancer survivors, by age
Log income
.4
.2
0
-.2
-.4
-5
-4
-3
-2
-1
0
1
2
3
4
5
Year before/after diagnosis
18-29
30-64
65+
Results from age-adjusted fixed-effects models using dummies for each year pre/post diagnosis.

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