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The Medical Expenditure Panel Survey (MEPS) Experiences with Cancer Survivorship Supplement

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Abstract

Introduction—The prevalence of cancer survivorship in the USA is expected to increase in the future because the US population is increasing in size and is aging and because survival following diagnosis is improving for many types of cancer. Medical care costs associated with cancer are also projected to increase dramatically. However, currently available data for estimating medical care costs and other important aspects of the burden of cancer, including time spent receiving medical care, productivity loss due to morbidity for patients and their families, and financial hardship, are limited, particularly in the population under the age of 65.

Methods—We describe selected publicly available data sources for estimating the burden of cancer in the USA and a new collaborative effort to improve the quality of these data: the nationally representative Medical Expenditure Panel Survey (MEPS) Experiences with Cancer Survivorship Supplement.

Conclusions—Data from this effort can be used to address key gaps in cancer survivorship research related to medical care costs, employment patterns, financial hardship, and other aspects of the burden of illness for cancer survivors and their families.

Implications for cancer survivors—Research using the MEPS Experiences with Cancer Survivorship Supplement can inform efforts by health care policy makers, healthcare systems, providers, and employers to improve the cancer survivorship experience in the USA.

Keywords

Cost of illness; Health care expenditures; Burden of illness; Neoplasms; SEER-Medicare; NHIS; MEPS

Introduction

In January 2008, approximately 12 million individuals in the USA were alive with a previous cancer diagnosis [1]. Although overall cancer incidence rates have declined in recent years [1, 2], the absolute number of cancer survivors is expected to increase significantly in the future [2, 3] because the US population is both increasing in size and life expectancy. In addition, advances in early detection and effective treatments are associated with improved survival following diagnosis [4]. The majority of this increase in survivorship is expected in the elderly, those aged 65 and older, because total cancer incidence is highest in this group [3]. The projected number of working age cancer survivors (i.e., those younger than 65) is also expected to be sizable [3].

Based on dynamic US population projections and currently available data, the national medical care costs associated with cancer are expected to be at least $157.8 billion dollars by the year 2020 [3]. In addition to medical care costs, other important components of the burden of cancer include the time spent receiving medical care, time lost from work or other usual activities due to morbidity, adverse quality of life and other psychosocial outcomes, and the late or lasting effects of treatment on patients and families. These aspects of cancer burden may persist many years following a cancer diagnosis [5, 6]. Cancer and its treatment can also result in financial hardship for patients and their families, and some cancer survivors forego medical care because of its cost [7, 8]. Because health insurance in the working age population is predominantly employment-based in the USA, understanding the complex relationship between employment, health insurance coverage, access to care, and burden of cancer is critical for improving survivorship experiences. To date, few national studies have been conducted to assess these multiple aspects of the burden of cancer in the USA, in part because comprehensive longitudinal national data are largely unavailable.

The 2005 Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition,* highlighted key gaps in cancer survivorship research, including the need for national estimates of the burden of cancer, research on the financial impact of cancer on survivors and their families, and studies of workplace outcomes and patterns of employment [9]. Information about employment patterns, access to care, barriers to obtaining health insurance or being underinsured, and the associated long-term financial burden to cancer survivors and their families are particularly germane in relation to the anticipated expansion of health insurance coverage and efforts to minimize coverage exclusions for pre-existing conditions resulting from the Affordable Care Act, passed in March 2010 [10].

In this paper, we review types of existing publicly available data sources for estimating the burden of cancer in the USA and describe the Medical Expenditure Panel Survey (MEPS) Experiences with Cancer Survivorship Supplement, a collaborative effort to improve the quality of these data and inform efforts to reduce the burden of cancer on patients, families, employers, and society overall.

Data sources for estimating the burden of cancer in the USA

Many types of data are available for estimating specific aspects of the burden of cancer in the USA, including hospital discharge data, health insurance claims, and household surveys [11, 12]. Selected publicly available data sources that are commonly used to estimate aspects of the burden of cancer are listed in Table 1, including the Healthcare Costs and Utilization Program (H-CUP) hospital discharge data, the linked Surveillance Epidemiology and End Results tumor registry-Medicare data (SEER-Medicare), the National Health Interview Survey (NHIS) and the MEPS. Features of these data sources are reviewed below, including population coverage, information about cancer diagnosis, and availability of information about the burden of cancer, including medical care costs, time spent seeking medical care for patients and caregivers, and lost productivity, across the trajectory of cancer, from diagnosis through the end of life.

Healthcare Costs and Utilization Project—The H-CUP is a family of national and state healthcare databases and tools sponsored by the Agency for Healthcare Quality and Research (AHRQ) and includes the Nationwide Inpatient Sample (NIS) and State Inpatient Databases (SID), Nationwide Emergency Department Sample and State Emergency Department Databases, and State Ambulatory Care Databases. The NIS and SID include medical care use and associated costs for individuals of all ages with all types of health insurance, but primarily for one aspect of medical care, inpatient hospitalizations [13]. These NIS data have been available every year since 1988. The unit of observation is the hospitalization rather than the individual patient, so multiple hospitalizations for the same person are unique observations in the NIS and cannot be linked at the individual level to provide longitudinal information about care. In some states, linkage for multiple hospitalizations and across H-CUP databases is available, although these data have not been commonly used to estimate cancer burden. Although millions of cancer survivors can be identified in the NIS by diagnosis and procedure codes, information about date of diagnosis, stage, additional cancers, pre-hospitalization comorbidity, and other factors that influence patient eligibility for specific treatments is not available. Furthermore, information about cancer survivors treated outside of the hospital inpatient setting (e.g., prostate cancer patients treated with radiotherapy) is unavailable in the NIS. The NIS has been mainly used to estimate the use and costs of surgery among hospitalized cancer survivors [14, 15].

Linked SEER-Medicare data—The linked SEER-Medicare data are made available by the National Cancer Institute (NCI) and contain longitudinal information about medical care and associated payments received before, during, and after cancer diagnosis for Medicare beneficiaries [16]. Information about cancer diagnoses is available for the years each geographically defined registry has been part of the SEER program, starting in 1973. Medicare claims since 1991 are available for two cohorts of beneficiaries included in the SEER-Medicare data—cancer survivors and a random sample of Medicare beneficiaries residing in the SEER areas who do not have cancer. Because more than 95 % of individuals over the age of 65 in the USA are enrolled in the Medicare program, and SEER registries currently cover approximately 26 % of the US population, these national data reflect cancer care for a large portion of the elderly in the USA. More than three million cancer survivors can be identified from SEER-Medicare with detailed information about cancer stage, grade and histology for each diagnosis. Identification of incident cancer patients and patients with multiple cancers is another strength of the linkage of health insurance program data with cancer registry data.

As with other health insurance program data, Medicare claims do not contain any information about individuals without health insurance or the utilization and costs of specific services covered by other insurance programs or those services paid entirely out-of-pocket. Medicare payments are thought to represent approximately 51 to 65 % of all medical care costs in the elderly [17, 18], with the remaining costs covered by other insurers or by out-of-pocket payments. The proportion of Medicare payments for total costs of cancer care is unknown. These linked SEER-Medicare data have been used extensively to estimate the costs of medical care associated with cancer in the elderly [3, 19, 20]. Additionally, the costs associated with patient time have been estimated from patients' medical service frequencies (e.g., hospital length of stay, physician visits, and chemotherapy) combined with average service specific time estimates [21]. Notably, SEER-Medicare cannot be used to estimate costs associated with cancer care in the working age population under the age of 65, and information about employment and health status are unavailable.

National Health Interview Survey—The NHIS is a nationally representative household survey of the non-institutionalized civilian population in the USA conducted annually since 1957 by the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) [22]. The NHIS collects demographics and cross-sectional information about medical conditions, health status, health behaviors, access to medical care, and employment for individuals aged 18 and older with all types of health insurance. However, cancer care utilization and costs of care are not covered (Table 2). Cancer survivors can be identified based on their response to the question “Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?” This question about cancer diagnoses is asked only of a single adult aged 18 and older in each family (i.e., NHIS Sample Adult). Cancer survivors experiencing medical conditions or health limitations due to cancer at the time of the survey can also be identified from the core portion of the survey.

The NHIS included Cancer Control Supplements in 1987, 1992, 2000, 2005, and 2010, which were completed by the sampled adult in each family. These supplements contained detailed questions about topics such as family history of cancer, sun exposure, tobacco use, alcohol consumption, diet, and physical activity; screening for breast, cervical, colorectal, and prostate cancers; and genetic testing. The 2010 NHIS Cancer Control Supplement included a section about cancer survivorship; however, few questions were specific to the burden of cancer (Table 2).

Nationally representative surveys such as the NHIS are limited by small numbers of patients who are newly diagnosed or diagnosed with cancers associated with short survival (e.g., lung) or low incidence (e.g., testicular). Details about cancer diagnosis, including stage, clinical characteristics and other prognostic information, and treatment are generally not available. Because questions are not specific to burden of illness related to cancer, the NHIS has been previously used to assess employment, insurance coverage, access to care and health status in cancer survivors compared with individuals without cancer [5-7, 23, 24].

Medical Expenditure Panel Survey—The MEPS is an annual nationally representative survey which is conducted in a subsample of respondents from the prior year NHIS [25] by the AHRQ. The MEPS was first fielded in 1996 and consists of three surveys: the Household Component (HC), the Medical Provider Component (MPC), and the Insurance Component (IC). The MEPS-HC collects demographic, health status, access to medical care, employment, and health care use and expenditure data for individuals of all ages, with all insurance types (Table 2). The MEPS also collects data for individuals without health insurance. The MEPS-MPC provides additional information on charges, sources, and amounts of payment received by providers (physicians, hospitals, home health agencies, and pharmacies) for care delivered to participants in the household survey. The MEPS-IC is a separate survey of employers that provides data on employer-based health insurance.

The MEPS-HC uses an overlapping panel design (Fig. 1), in which each panel consists of individuals who are interviewed in-person 5 times or rounds over about 2.5 years. Data from two panels are combined to produce estimates for each calendar year and each panel separately produces longitudinal estimates over 2 years [25]. Each panel can also be linked with the prior year NHIS for up to three years of observation. Through 2007, cancer survivors were only identified in the MEPS if they received care for cancer, or missed work or school or spent a day in bed because of cancer during the survey period ("treated prevalence"). Cancer survivors have been reported to have higher costs of care and health limitations for many years following diagnosis than individuals without cancer [5, 6, 26], suggesting that the "treated prevalence" definition used by the MEPS through 2007 is incomplete for understanding the burden of cancer. Because MEPS respondents are a subsample of the NHIS and a "treated prevalence" definition was used from 1996 to 2007, only very small numbers of cancer survivors were identified in a given year during this period.

Starting in 2008 (panels 12 and 13), a new question about a cancer diagnosis was added for adults aged 18 and older in rounds 3 and 5. Rather than only identifying the subset of cancer survivors undergoing cancer treatment at the time of the survey, this change now results in the identification of all individuals with a history of cancer, consistent with definitions of cancer survivorship used elsewhere, including the NHIS. Notably the question about a cancer diagnosis is asked for all adults in the family, making the MEPS one of the only data sources to identify cancer history for the family. As with the NHIS, details about cancer diagnosis, including, stage, tumor characteristics and other prognostic information are unavailable. Some studies have therefore combined many years of the MEPS to describe healthcare utilization and expenditures in cancer survivors receiving cancer care compared with individuals without cancer [26-30]. Even with many years of data and linkage to the NHIS, some aspects of cancer burden still cannot be measured, however.

As described above and illustrated in Table 1, there are currently limitations with each of the most commonly used publicly available data for estimating the burden of cancer in the USA. No single data source contains comprehensive longitudinal information for large numbers of cancer survivors about multiple health care services across insurance type (including the uninsured) in the elderly or in younger populations. Furthermore, few data sources contain information about non-medical components of the burden of cancer, including patient and caregiver time and lost productivity [11]. These gaps are particularly notable in cancer survivors under the age of 65, who are a key population for understanding the national burden of cancer, particularly in relation to employment patterns and health insurance. To begin to address these multiple data gaps and research needs, the NCI, the CDC, the American Cancer Society (ACS), the National Institutes of Health Office of Behavioral and Social Sciences Research, and the LIVESTRONG foundation have collaborated with the AHRQ to improve the quality of publicly available data for estimating the burden of cancer in the USA. In the following sections, we describe the MEPS Experiences with Cancer Survivorship Supplement and highlight opportunities for researchers to utilize these data to address key questions in cancer survivorship.

The MEPS Experiences with Cancer Survivorship Supplement

The MEPS Experiences with Cancer Survivorship Supplement consists of two components: (1) an oversample of households with cancer survivors from the NHIS for inclusion in the MEPS, and (2) a self-administered questionnaire of cancer survivors with detailed questions about burden of cancer, including access to healthcare, employment patterns in survivors and caregivers, lost productivity, financial issues, and the psychosocial impacts on survivors and their families [31]. The MEPS Supplement started in 2011, in MEPS panels 15 and 16, selected from the 2009 and 2010 NHIS, respectively. These years were chosen to maximize the utility of these data for research on the burden of cancer. As noted previously, the 2010 NHIS included a Cancer Control Supplement, which can be linked to information about health care use and expenditures for MEPS panel 16 respondents starting in 2011 through 2012.

Additionally, the timing of the MEPS Experiences with Cancer Survivorship Supplement coincides with the recent change in how cancer survivors are identified in the MEPS to include all adults in the family with a history of cancer. Importantly, this new question about cancer diagnosis is asked for all MEPS respondents, and not just the sampled adult in each family. In the following sections, we describe the oversampling of households with cancer survivors included in the MEPS panel 16 and describe the MEPS *Experiences with Cancer* questionnaire, which will be administered to approximately 2,000 cancer survivors in MEPS panels 15 and 16 and will be publically available in the full year 2011 MEPS data.

Oversampling households with cancer survivors from the 2010 NHIS for inclusion in the MEPS panel 16—As described previously, a single adult in each family responded to the 2010 NHIS Cancer Control Supplement and indicated whether they had a personal history of cancer. Some of the 2010 NHIS households with identified cancer survivors were automatically included in the MEPS panel 16 because their household was part of routine MEPS sample selection (Fig. 2). All other households with a cancer survivor identified from the NHIS, but not part of the routine MEPS sample selection, were oversampled for inclusion in the MEPS panel 16 starting in 2011 and conducted through 2012. Finally cancer survivors who were not the sampled adult from their family in the NHIS or who were diagnosed after completing the NHIS were also identified from the core MEPS question about a prior cancer diagnosis that is asked for all adults.

MEPS Experiences with Cancer questionnaire—The self-administered questionnaire, *Experiences with Cancer,* was developed as a collaborative effort between scientists at NCI, CDC, ACS, AHRQ, and Westat. The questionnaire was designed to complement the domains already captured in the core MEPS, the core 2010 NHIS and NHIS Cancer Control Supplement. As shown in Table 2, detailed socioeconomic information about race, ethnicity, educational attainment and income are available from both the core NHIS and the core MEPS. Additionally information about general access to health care, health status and employment are available from both the core NHIS and the core MEPS. Detailed information about medical care use and expenditures across multiple health insurance providers is also well-collected in the core MEPS.

Building on a systematic review of existing survey instruments that assess cancer survivorship [32], the study team identified questions within key domains, including financial burden, access to medical care, employment patterns for cancer survivors and their caregivers, other aspects of productivity, and survivorship care. Domains and individual questions were assessed for inclusion in the questionnaire based on: (1) their relationship and overlap with domains and questions already available in the core NHIS and core MEPS; (2) their relevance for a broad sample of cancer survivors with multiple types of cancer across the trajectory of care following diagnosis, including newly diagnosed, those with recurrent disease, and long term survivors; (3) their associations with medical care utilization and expenditures and other aspects of burden of illness; and (4) the degree to which they minimized complexity when administered to a broad range of respondents. To the extent possible, prior experiences with specific questionnaire items and their performance characteristics were used to inform the selection process.

A final set of domains and questions were developed and reviewed further to eliminate duplication and assure the flow of questions. The questionnaire was then evaluated in cognitive testing [33] in both English and Spanish, where cancer survivors who completed the questionnaire were probed by specially trained interviewers with respect to cognitive processes invoked to respond to survey questions, including item comprehension, information retrieval, and judgment, estimation, and response processes [34]. Approximately 60 cancer survivors with different levels of educational attainment, types of health insurance, employment status, and time since cancer diagnosis participated in several rounds of cognitive testing. Subsequent to this testing phase, questions that were found to present wording or other problems were modified to address the cognitive problems identified, and the MEPS *Experiences with Cancer* questionnaire was finalized. The questionnaire will be fielded in MEPS panel 15 round 5 and panel 16 round 3 and data will be available in the full year 2011 MEPS public use files (Fig. 3).

Examples of studies of burden of illness in cancer survivors that can be conducted with the MEPS Experiences with Cancer Survivorship Supplement

In this section, we refer to information about domains contained in the MEPS *Experiences with Cancer* questionnaire, core MEPS, NHIS Cancer Control Supplement and the core NHIS (see Table 2) to illustrate examples of the types of studies and study questions that can be addressed with the MEPS Experiences with Cancer Survivorship Supplement. We also present data for cancer survivors and individuals without cancer from the most recent year of publicly available MEPS data. In 2009, 1767 cancer survivors were identified in the core MEPS, excluding those diagnosed only with non-melanoma skin cancer. Of this group, the most common cancer diagnoses were breast (N=332) and prostate cancers (N=252). The majority of cancer survivors were diagnosed six or more years prior to the survey (N=990), with the remaining survivors diagnosed 2-5 years (N=425), and less than 2 years prior to the survey (N=194). Table 3 provides information about cancer survivors and individuals without cancer by sex, race/ethnicity, marital status, educational attainment, employment, family income as a percentage of the poverty line, health insurance, usual source of care, and area of residence. Distributions are reported separately for the population aged 18-64 and aged 65 and older to aid in planning studies of health insurance and employment. Notably, the population of cancer survivors aged 18-64 is slightly larger than the population aged 65 and older.

It is expected that the sample of the MEPS Experiences with Cancer Supplement will include approximately 2000 cancer survivors with similar distributions as reported here. These data will support many types of study designs, including: (1) cross-sectional studies of cancer-specific burden of illness using the MEPS Supplement questionnaire; (2) cross-sectional studies of burden of illness in cancer survivors compared with individuals without cancer based on the core MEPS; (3) longitudinal studies of cancer survivors and individuals without cancer using the core MEPS or linked NHIS-MEPS; and (4) longitudinal studies with detailed cancer control and cancer burden of illness information in cancer survivors using a linkage between the NHIS Cancer Control Supplement and the MEPS Experiences with Cancer questionnaire. We next present potential research questions related to the domains of access to care, healthcare utilization and expenditures, and employment patterns.

Access to medical care in cancer survivors—As shown in Table 2, information about access to medical care in general is collected in the core MEPS and within the core NHIS. Information about cancer-specific access to care will be collected in the MEPS *Experiences with Cancer* questionnaire. Information about family history of cancer is collected in the NHIS Cancer Control Supplement. Sample research questions that could be addressed through use of these data include the following:

- What proportion of cancer survivors report problems with access to medical care compared with individuals without cancer (core MEPS)?
- What proportion of cancer survivors report problems with access to *cancer care* (MEPS *Experiences with Cancer* questionnaire)?
- Do problems with access to medical care change over time for cancer survivors compared with individuals without cancer (linked NHIS-MEPS)?
- Is previously reported family history of cancer associated with access to medical care for cancer survivors and individuals without cancer (linked NHIS Cancer Control Supplement-MEPS)?

Medical care utilization and expenditures in cancer survivors—Information about utilization and expenditures is available from the core MEPS. Sample research questions include:

- Do cancer survivors have greater health care utilization than individuals without cancer? Do cancer survivors have greater expenditures than individuals without cancer (core MEPS)?
- Is a family history of cancer associated with similar trajectories of health care utilization for cancer survivors and individuals without cancer? (linked NHIS Cancer Control Supplement-MEPS)?

Employment in cancer survivors and caregivers—Questions about employment are included in the core NHIS, NHIS Cancer Control Supplement, core MEPS and the MEPS *Experiences with Cancer* questionnaire. Examples of research questions include:

- Do cancer survivors adjust employment because of cancer? (MEPS *Experiences with Cancer* questionnaire)
- Do informal caregivers adjust employment because of cancer? (MEPS *Experiences with Cancer* questionnaire)
- What are employment trajectories in cancer survivors compared with individuals without cancer (linked NHIS Cancer Control Supplement-MEPS; core MEPS)?

Discussion

As described in this paper, the MEPS Experiences with Cancer Survivorship Supplement will provide information currently unavailable from other sources about the national burden of cancer in the USA, including medical care utilization and expenditures, financial impacts, and employment patterns following a cancer diagnosis for survivors and their families and caregivers. Additionally, because respondents to the MEPS are a subsample of the NHIS, these data can also be linked to the core NHIS and the 2010 NHIS Cancer Control Supplement to provide some of the most comprehensive publically available longitudinal data for measuring burden of cancer in the USA across multiple domains. These data can be used to address key gaps in cancer survivorship research, including many identified in the 2005 Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition* [9]. Research on burden of illness associated with cancer and its treatment using these data will have broad policy implications, and findings can be used to inform the setting of public and private budgets, structuring of insurance, employee benefits and establishing reimbursement rates. Even though the focus of this overview paper has been on economic aspects of cancer burden, the MEPS Supplement will also improve research capacity in other aspects of cancer burden, such as medical comorbidities, psychological distress and quality of life. Studies using these data may also have utility for health care providers when discussing late and long-term effects of cancer and its treatment.

An important strength of these data for cancer survivorship research is the substantial numbers of survivors under the age of 65 in a nationally representative sample. Unlike the population aged 65 and older who receive insurance coverage through the Medicare program, a significant portion of the under 65 population do not have health insurance [24, 35], and information about their utilization and expenditures is not readily available elsewhere. Additionally, cancer care has been reported to be more aggressive in younger than older cancer patients [36-38], potentially resulting in greater medical cost, productivity loss, late and long-term effects, and other impacts. These outcomes are particularly striking when compared with younger individuals without cancer who are less likely to have comorbid conditions than the elderly. Finally, this group may spend more years living with any lasting effects of cancer or its treatment and experience different types of late effects than survivors diagnosed with cancer at older ages. Thus, by including medical care utilization and cost data along with information about employment patterns, health insurance and access to care, the MEPS Experiences with Cancer Survivorship Supplement will be a critical source of information for understanding the burden of cancer in the working age population.

These multiple components of cancer burden, including medical care expenditures, financial burden, and employment patterns, will all be available in a single nationally representative sample of cancer survivors with all types of health insurance. Others have shown differences in burden of illness estimates, even in similar populations, based on the source of data [27, 39] and methods for identifying cancer survivors [27, 39, 40]. Because the MEPS contains comprehensive expenditure information from multiple payers for cancer survivors of all ages, studies using these data may inform understanding of the impact of missing elements from other data sources. For example, national estimates of expenditures associated with cancer based on the linked SEER-Medicare data typically make assumptions about missing information for non-Medicare payments and out-of-pocket expenses [3, 19]. Head-to-head comparisons of medical care expenditures in similar populations of cancer survivors and individuals without cancer from the MEPS and SEER-Medicare could inform these assumptions in the future.

Although the MEPS Experiences with Cancer Survivorship Supplement will capitalize on existing NHIS and MEPS data to provide rich breadth and depth of information on health insurance, access to care, medical care use, expenditures, and employment, there will still be some limitations to these data. As with other household surveys, the MEPS does not include individuals in institutions, which excludes some high-cost populations in long-term care. Because the survey also depends on self-report of medical events and consequences, there might be under, or over, reporting of some events or misreporting by respondents of medical conditions of family members within the household. Furthermore, detailed information about cancer stage or other tumor and clinical characteristics are not collected and information about specific treatments is limited. Because the maximum duration of observation based on linkage to the NHIS is three years, it is unlikely that the full trajectory of illness from diagnosis to death will be included in this time frame for most individuals.

Nationally representative population-based surveys identify cancer survivors who are alive at the time of the survey and generally include only small numbers who have been newly diagnosed, have rare cancers or who have cancers associated with short survival (e.g., lung and pancreas). Because the cancer diagnosis question in both the NHIS Cancer Control Supplement and the core MEPS is only asked of the population aged 18 and older and we also restricted the *Experiences with Cancer* questionnaire to the adult population, these data will not be useful for studying recently diagnosed pediatric cancers. Furthermore, seriously ill individuals may be less likely to respond to a survey. As a result, cancer survivors included in population-based surveys such as the NHIS or MEPS tend to mainly consist of long term survivors of common adult cancers (e.g., breast and prostate), often participating many years after their cancer diagnosis.

Overall, the MEPS Experiences with Cancer Survivorship Supplement provides a valuable resource for the cancer research community to explore important questions on burden of cancer, medical care use, expenditures, financial burden, employment and employment patterns, and workplace accommodations. This work may help highlight a greater need for public health research and programs to address inequalities related to cancer burden, access to and use of medical care among cancer survivors. Findings from this research will provide key information needed for the development of interventions to improve the quality of the cancer survivorship experience, as well as pivotal information for policy makers in understanding and reducing the burden of cancer in the USA.

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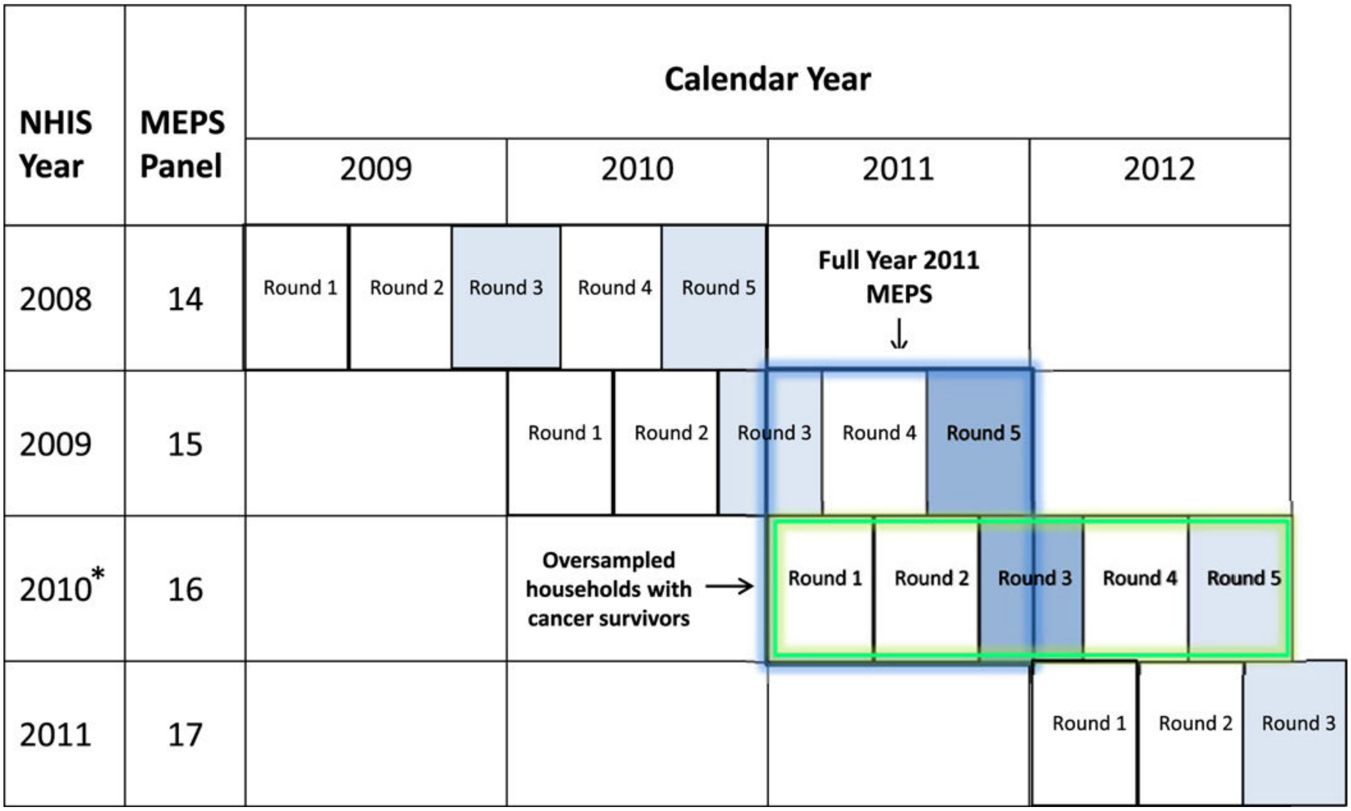

Fig. 1.

National Health Interview Survey (NHIS) and the Medical Expenditure Panel Survey (*MEPS*) overlapping panel design. Questions about cancer diagnosis (light blue) are completed in rounds 3 & 5 in all years MEPS Experiences with Cancer questionnaire (dark blue) will be completed by panel 15 round 5 and panel 16 round 3 * NHIS 2010 Cancer Control Supplement used to oversample households with cancer survivors for MEPS panel 16 (green box)

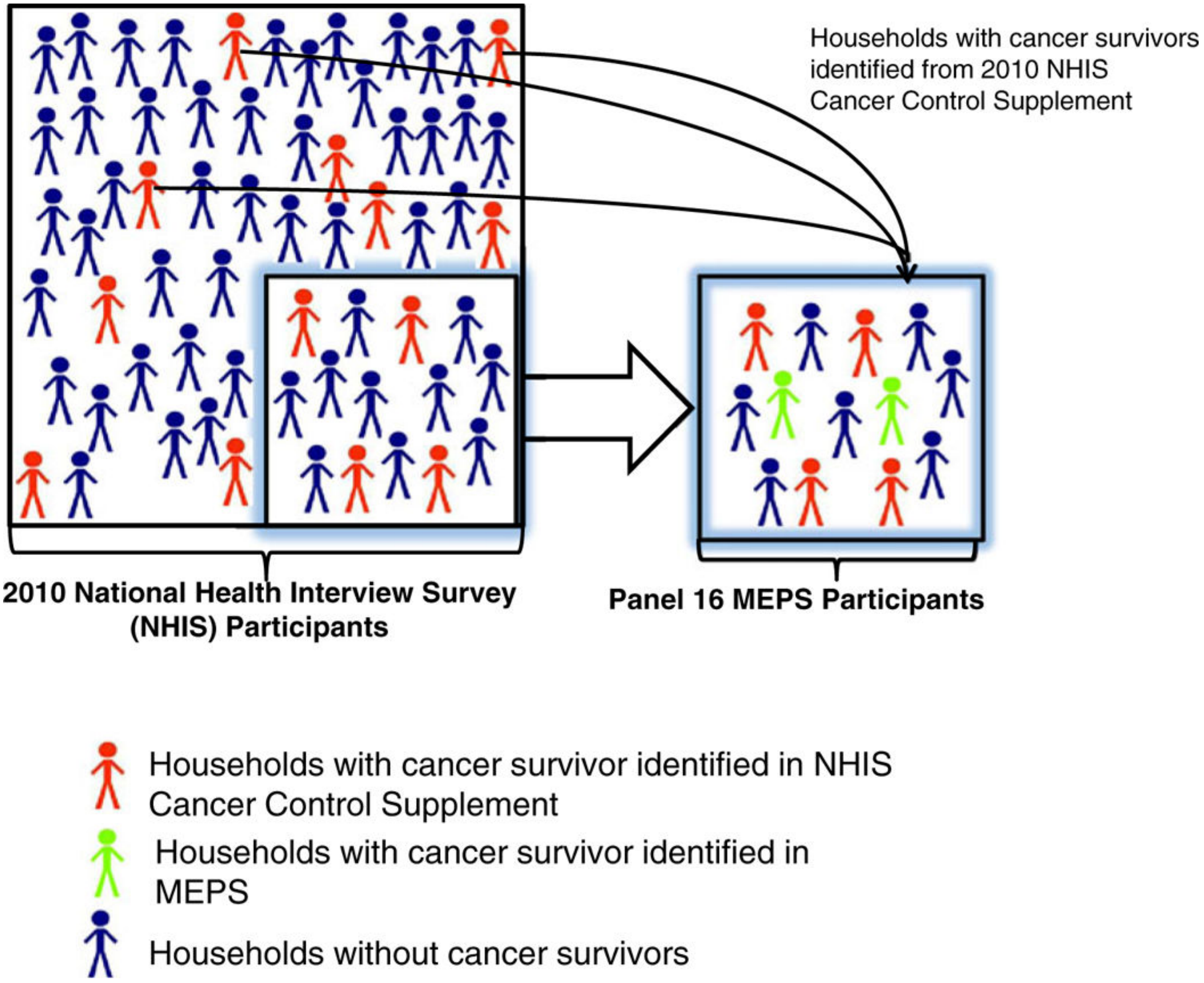

Fig. 2.

Medical Expenditure Panel Survey (*MEPS*) Experiences with Cancer Survivorship Supplement: oversampling households with cancer survivors

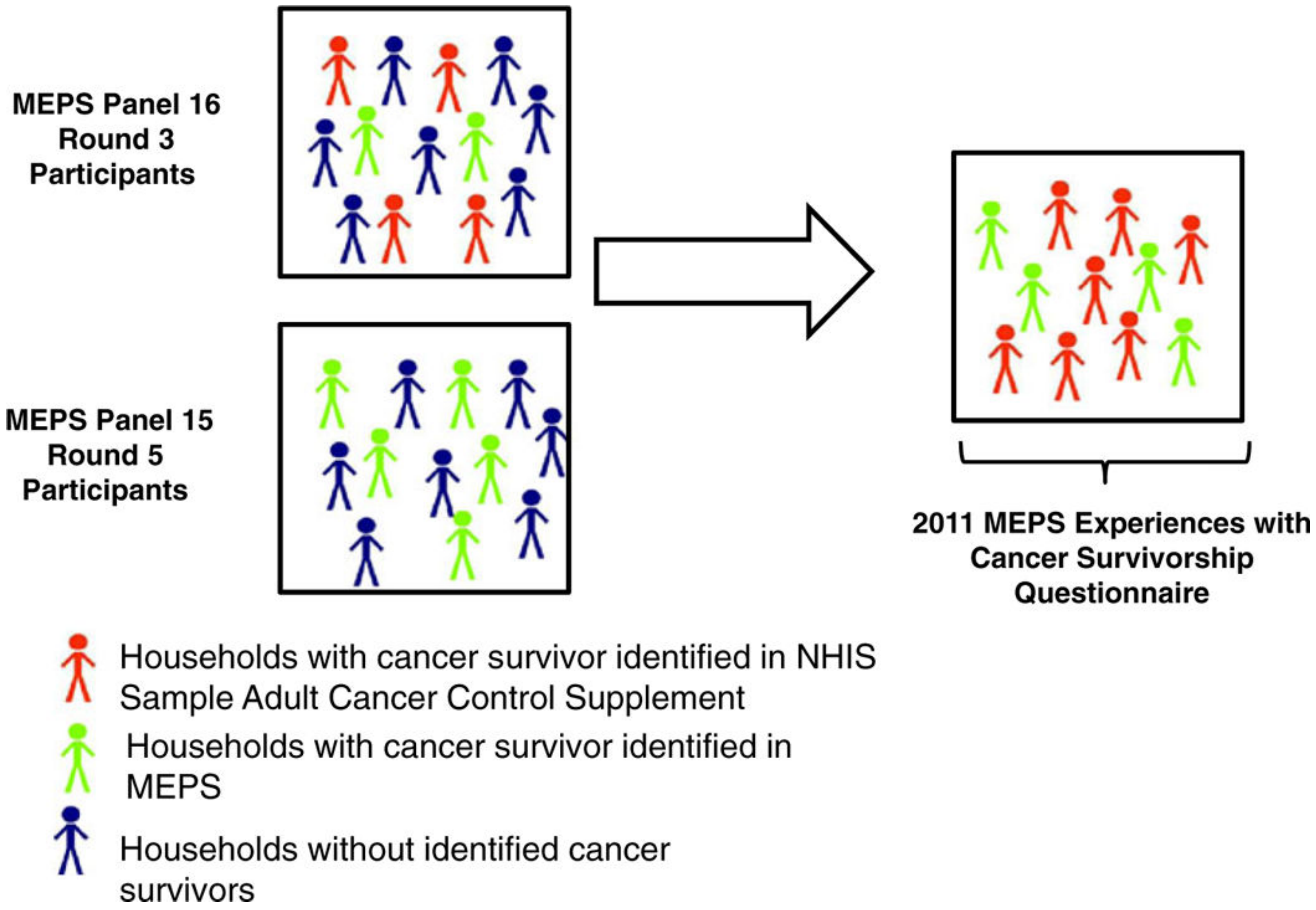

Fig. 3.

Medical Expenditure Panel Survey (*MEPS*) Experiences with Cancer Survivorship Supplement: survey participants

Table 1

Characteristics of selected publically available data sources for estimating burden of cancer in the USA

	Healthcare Costs and Utilization Project (H-CUP) Nationwide Inpatient Sample (NIS) and State Inpatient Databases (SID)	**Surveillance Epidemiology and End Results-Medicare (SEER-Medicare)**	**National Health Interview Survey (NHIS)**	**Medical Expenditure Panel Survey (MEPS) 1996–2007**
Description	Inpatient databases with discharge data from sampled hospitals	SEER tumor registries linked to Medicare claims	Nationally representative household survey	Nationally representative household survey with provider data collection
Data characteristics				
National or nationally representative	√	Geographically defined	√	√
Unit of observation	Discharge[a]	Individual	Individual	Individual
Longitudinal data		√		2 years, up to 3 years with NHIS linkage
Inclusion of eligible individuals	All hospitalized	Linked to Medicare enrollment	61–80 % response rates	60–80 % response rates
Approximate number of cancer survivors in 2007	>1,000,000	>3,000,000	<2,000	<1,000
Health insurance	All payers	Medicare fee-for-service only	All payers	All payers
Patient information				
Ages included	All ages	Aged 65+	All ages	All ages
Gender, race/ethnicity	√	√	√	√
Educational attainment/income			√	√
Individuals without cancer	√	In cancer registry regions	√	√
Cancer information				
Cancer diagnosis/identification method	Procedure or diagnosis codes	Registry	Self-report	Self-report
Diagnosis date/year		√	√	√
Multiple cancers		√	√	√
Stage		√		
Treatment	Inpatient hospital only	√		During survey period
Medical care costs or expenditures				
Hospital	√	√		√
Physician and other outpatient services		√		√

	Healthcare Costs and Utilization Project (H-CUP) Nationwide Inpatient Sample (NIS) and State Inpatient Databases (SID)	Surveillance Epidemiology and End Results-Medicare (SEER-Medicare)	National Health Interview Survey (NHIS)	Medical Expenditure Panel Survey (MEPS) 1996–2007
Outpatient pharmacy		√[b]		√
Out of pocket				√
Other aspects of burden of illness				
Time lost from work			√	√
Patient time		√[c]		√[c]
Caregiver time				
Health status			√	√
Selected medical conditions	Procedure or diagnosis codes	Procedure or diagnosis codes	Self-report	Self-report
Functional status			√	√

Domains in the H-CUP, NHIS and MEPS are generally not cancer specific, but can be evaluated among cancer survivors or comparisons can be made between cancer survivors and individuals without cancer

[a] Linkage between multiple hospitalizations for the same individual is possible in some states as part of the SID

[b] Data on Medicare Part D prescription drug services are available starting in 2006. Before 2006, drugs administered parenterally and their administration was covered by Medicare Part B, as were Prodrugs, the oral drug equivalent of drugs administered parenterally

[c] Patient time can be estimated from service use frequency and service specific time estimates

Table 2

Domains and Measures in the Core 2010 National Health Interview Survey (NHIS) and Cancer Control Supplement and 2011 Medical Expenditure Panel Survey (MEPS) and MEPS Experiences with Cancer Survivorship Questionnaire

		2010 NHIS		**2011 MEPS**	
Domain	**Measure**	**Core**	**Cancer Control Supplement**	**Core**	**Experiences with Cancer Survivorship Questionnaire**
Patient information					
Socioeconomic characteristics	Gender, race/ethnicity	√		√	
	Educational attainment, income	√		√	
	Employment (Full time and part time)	√		√	
Health insurance	Coverage and type (e.g., Medicare and Medicaid)	√	√	√	
	Premium payments and deductibles	√		√	
	Health insurance through employment	√		√	
	Changes in health insurance because of cancer				√
Cancer information					
Risk Factors	Family history of cancer		√		
	Tobacco and alcohol use		√		
	Physical activity		√		
	Diet and nutrition		√		
Cancer screening	Breast, cervical, colorectal, and prostate		√	√	
Cancer status	*Current cancer status/recurrence*		√	√	√
	Most recent cancer treatment		√	√[a]	√
	Timing of most recent cancer treatment				√
Medical care utilization and expenditures					

		2010 NHIS		2011 MEPS	
Domain	**Measure**	**Core**	**Cancer Control Supplement**	**Core**	**Experiences with Cancer Survivorship Questionnaire**
Medical care services	Hospitalizations and expenditures			√	
	Office-based visits and expenditures			√	
	Hospital outpatient visits and expenditures			√	
	Emergency room visits and expenditures			√	
	Prescription drugs and expenditures			√	
	Out of pocket expenditures			√	
	Provider recommendations for cancer survivorship care				√
Access to health care	Delayed or did not get any needed health care	√		√	
	Delayed or did not get any needed cancer care				√
Other aspects of burden of illness					
Employment	Limited in amount or type of work	√		√	
	Changes in work because of cancer				√
	Duration of work changes because Of cancer				√
	"Job lock" to maintain health insurance because of cancer				√
	Limitations in work because Of cancer				√
	Changes in caregiver work because of cancer				√
	Duration of caregiver work changes				√
Financial impact	*Financial problems because of cancer*		√		√

Domain	Measure	2010 NHIS Core	2010 NHIS Cancer Control Supplement	2011 MEPS Core	2011 MEPS Experiences with Cancer Survivorship Questionnaire
	Medical debt because of cancer				√
Physical and Emotional Health	Activities of daily living	√	√	√	
	Health status	√		√	
	Emotional problems, fatigue, and pain		√	√	
	Worry about cancer recurrence				√
	Positive aspect of experiences with cancer				√
	Medical conditions/comorbidity	√	√	√	
	Limitations in activities due to cancer				√

Domains in the core NHIS and core MEPS are generally not cancer-specific but can be evaluated among cancer survivors or comparisons can be made between cancer survivors and individuals without cancer. Italicized measures are those included in the MEPS Experiences with Cancer Survivorship Questionnaire

[a] Information about cancer treatment during the period of the survey is available in the MEPS, but is not available if it occurred prior to or after the survey period

Table 3

Characteristics of cancer survivors and individuals without cancer in 2009 MEPS

	Aged 18–64				Aged 65+			
	Cancer survivors (*N*=899)		Individuals without cancer (*N*= 20,069)		Cancer survivors (*N*=868)		Individuals without cancer (*N*=2,992)	
	n	**Wgtd %**[a]	***n***	**Wgtd %**[a]	***n***	**Wgtd %**[a]	***n***	**Wgtd %**[a]
Sex								
Male	268	34.1	9,556	50.3	415	48.1	1,200	41.5
Female	631	65.9	10,513	49.7	453	51.9	1,792	58.5
Race/ethnicity								
Non-Hispanic white only	589	82.8	8,344	64.9	650	86.9	1,700	76.9
Non-Hispanic black only	138	7.2	3,979	12.3	118	6.5	576	9.2
Hispanic	131	6.8	5,809	15.6	64	4.2	439	8.2
Non-Hispanic other/multiple	41	3.1	1,937	7.2	36	2.5	277	5.7
Marital status								
Married	512	61.7	10,271	52.9	456	53.7	1,517	53.6
Not married	387	38.3	9,798	47.1	412	46.3	1,475	46.4
Education when first entered MEPS[b]								
Less than high school grad	167	12.6	4,792	16.7	224	19.6	969	24.6
High school graduate	281	31.3	6,105	29.9	277	34.9	976	35.7
Some college or more	448	56.0	9,084	53.1	364	45.2	1,028	39.3
Employed during 2009[b]								
Yes	558	66.6	15,408	80.8	129	15.2	594	21.4
No	329	32.3	4,487	18.5	704	80.7	2,304	75.0
Family income as percent of poverty line								
Poor/near poor	218	16.9	4,706	16.5	187	16.6	717	16.7
Low income	123	11.5	3,245	12.9	136	15.6	555	17.8
Middle income	239	26.8	6,228	30.4	268	31.0	933	31.9
High income	319	44.9	5,890	40.2	277	36.9	787	33.6
Usual source of healthcare								

	Aged 18–64				**Aged 65+**			
	Cancer survivors (*N*=899)		**Individuals without cancer (*N*= 20,069)**		**Cancer survivors (*N*=868)**		**Individuals without cancer (*N*=2,992)**	
	n	**Wgtd %**[a]	***n***	**Wgtd %**[a]	***n***	**Wgtd %**[a]	***n***	**Wgtd %**[a]
Yes	763	85.1	13,274	69.9	782	91.4	2,617	88.1
No/missing	136	14.9	6,795	30.1	86	8.6	375	11.9
Health insurance[b]								
Age <65 (any private)	584	75.1	12,236	70.6				
Age <65 (public only)	211	15.4	2,827	9.8				
Age <65 (uninsured)	104	9.5	5,006	19.6				
Age 65+ (Medicare only)					329	36.9	1,135	39.2
Age 65+ (Medicare and private)					424	53.5	1,297	10.2
Age 65+ (Medicare and public)					107	8.8	505	10.2
Metropolitan statistical area								
Non-MSA	155	17.2	2,543	15.3	205	20.9	594	18.3
MSA	744	82.8	17,526	84.7	663	79.1	2,398	81.7
Geographic region								
Northeast	122	15.3	3,072	18.4	145	20.2	476	19.2
Midwest	212	23.7	3,876	21.7	187	22.6	585	22.2
South	344	37.2	7,554	36.5	355	37.2	1,188	36.8
West	221	23.8	5,567	23.4	181	19.9	743	21.9

[a] Estimates calculated with SUDAAN to incorporate the complex MEPS survey design and weighting for non-responses

[b] Missing data not reported