Original Article

Identifying and Describing Cancer Survivors: Implications for Cancer Survivorship Research and Clinical Care

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BACKGROUND: Gathering information directly from cancer survivors has advanced our understanding of the cancer survivorship experience. However, it is unknown whether surveys can distinguish important subgroups of cancer survivors. This study aimed to describe the current landscape of survey questions used to identify and describe cancer survivors in national cross-sectional studies. **METHODS:** Using publicly available databases, the authors identified national cross-sectional surveys used in the United States within the past 15 years that included a question on self-reported history of cancer. After abstracting questions and response items used to identify cancer survivors, they conducted a descriptive analysis. **RESULTS:** The authors identified 14 national cross-sectional surveys, with half administered to the general population and the other half administered to cancer survivors. The most common question used to identify cancer survivors was "Have you ever been told by a doctor or other health professional that you had cancer?" Most surveys had questions asking participants to identify a single cancer type (n = 11), multiple prior cancer diagnoses or types (n = 11), and the time from diagnosis (n = 12). Treatment questions varied from active treatment status to specific treatments received. Questions addressing cancer stage (n = 2), subtypes (n = 1), metastatic status (n = 3), and recurrence (n = 4) were less frequently included. **CONCLUSIONS:** There is no standard method for assessing self-reported cancer history, and this limits the ability to distinguish among potentially important subgroups of survivors. Future cross-sectional surveys that capture nuanced data elements, such as cancer types, stages/subtypes, metastatic/recurrent status, and treatments received, can help to fill important gaps in cancer survivorship research and clinical care. *Cancer* 2022;128:383-390. © 2021 The Authors. Cancer published by Wiley Periodicals LLC on behalf of American Cancer Society. This article has been contributed to by US Government employees and their work is in the public domain in the USA. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes..

KEYWORDS: cancer survivors, cross-sectional studies, health surveys, surveys and questionnaires.

INTRODUCTION

Cancer survivors are a heterogenous population. The term *cancer survivor* includes individuals after a cancer diagnosis and in active treatment; individuals living with cancer in remission; individuals living with recurrent, progressive, or metastatic cancer; individuals who have recently completed therapy; and long-term survivors free of cancer or "cured."[1-3] National organizations such as the National Cancer Institute, the American Cancer Society, the National Coalition for Cancer Survivorship, and the American Society of Clinical Oncology define a person to be a cancer survivor from the time of diagnosis through the end of life.[4-6] According to this definition, there are currently an estimated 16.9 million cancer survivors in the United States, with 5.5 million cancer survivors having survived 0 to <5 years, 3.8 million having survived 5 to <10 years, 4.5 million having survived 10 to <20 years, and 3.1 million having survived 20 or more years.[5] Although the definition of *cancer survivor* has evolved over time, with various proposed categories of survivorship (acute, chronic, long-term, or cured), not every individual diagnosed with cancer embraces this term and its use to identify and describe this population.[1,3,7-11]

Over the past several decades, cross-sectional surveys used to gather information directly from cancer survivors have provided important information on the experiences of cancer survivors, including physical effects, psychosocial concerns, health behaviors, health care utilization, and attitudes toward cancer-related information, among others.[11-16] Although there are linked data resources that connect self-reported survey data to a clinical diagnosis of cancer from medical records, administrative claims data, and/or cancer registries such as the Surveillance, Epidemiology, and End Results program, many surveys rely solely on self-reported identification of cancer survivors. From a research data collection perspective, it is efficient and reliable to ask individuals if they have ever been diagnosed with cancer; prior work has reported high concordance (96%) between self-reported "personal history of cancer" and medical records.[17] However, the findings and implications derived from surveys may have important limitations when relevant information such as the cancer type, time from diagnosis, or types of treatment received is not captured. The lack of these data can hinder the identification of unique acute, late, and long-term effects or subgroups of cancer survivors, and this may limit study findings.

To our knowledge, no studies have examined the questions used to identify and describe cancer survivors in national cross-sectional surveys. Therefore, the aim of this study was to capture the current landscape of survey questions used in cross-sectional research over the past 15 years to identify cancer survivors.

MATERIALS AND METHODS

We sought to identify publicly available cross-sectional research surveys that had published on cancer survivors. Databases that voluntarily host available surveys, including National Cancer Institute websites and the Inter-University Consortium for Political and Social Research Data Finder (using the search terms *cancer*, *United States*, *public use*, *survey*, *quantitative*, and *time period from 2005-2020*), were reviewed; public opinion and political polls were excluded because of their use for media purposes.[18-20] We also contacted and requested surveys from several cancer advocacy organizations known to conduct national surveys on cancer survivors and conducted a query search in Google using wording from cancer survivor questions identified from the databases. We did not include surveys used in other study designs (eg, cohort studies) because of differences in study objectives and sampling approaches.

We included surveys administered in the United States within the past 15 years, written in English, and publicly available online (Fig. 1). International surveys, including those available in English, were not included because the term *cancer survivor* is not uniformly used or accepted in other countries.[10,17] Institutional review board approval was not necessary for the conduct of this research as it does not involve human research participants and all data were in the public domain.

Surveys identified from the search strategy underwent initial screening to verify that the survey included at least 1 question on self-reported history of cancer and had at least 1 publication focusing on individuals with a history of cancer. Studies that explicitly stated that self-reported history of cancer was an exclusion criterion were excluded from the final analytic data set. If multiple versions of the survey were available, the most recent cancer survivorship version was selected. Supporting Table 1 lists the weblinks of the included surveys.

One reviewer (M.D.) abstracted the following information from the included surveys when it was available: year of the survey; population recruited for the survey; and questions, interviewer notes, and response items for 1) the identification of cancer survivors, 2) cancer type–single, 3) cancer types–multiple, 4) cancer stage, 5) molecular subtypes, 6) the presence of recurrent cancer, 7) the age at diagnosis or time from diagnosis, and 8) treatment (specifically whether on current treatment or the types of treatment received). After the initial survey screening, a subset of surveys (20%) was reviewed and abstracted by another reviewer (L.N.) to ensure agreement on the data abstraction methodology and the intercoder reliability of the information abstracted ($\kappa = 0.88$). We then conducted a descriptive analysis of the survey questions and synthesized the results as noted.

RESULTS

A total of 14 cross-sectional surveys met our final inclusion criteria and are listed in Table 1. The study population for half of the surveys consisted of cancer survivors only, whereas the other half included a broader population. The most common question used to identify cancer survivors in 10 of the surveys (71%) was "Have you ever been told by a doctor or other health professional that you had cancer?" or something similar (Table 2). The remaining surveys (n = 4; 29%) asked the following: "Have you ever been diagnosed with cancer?"

The majority of the surveys (n = 11; 79%) asked participants to report their cancer type. Ten surveys had
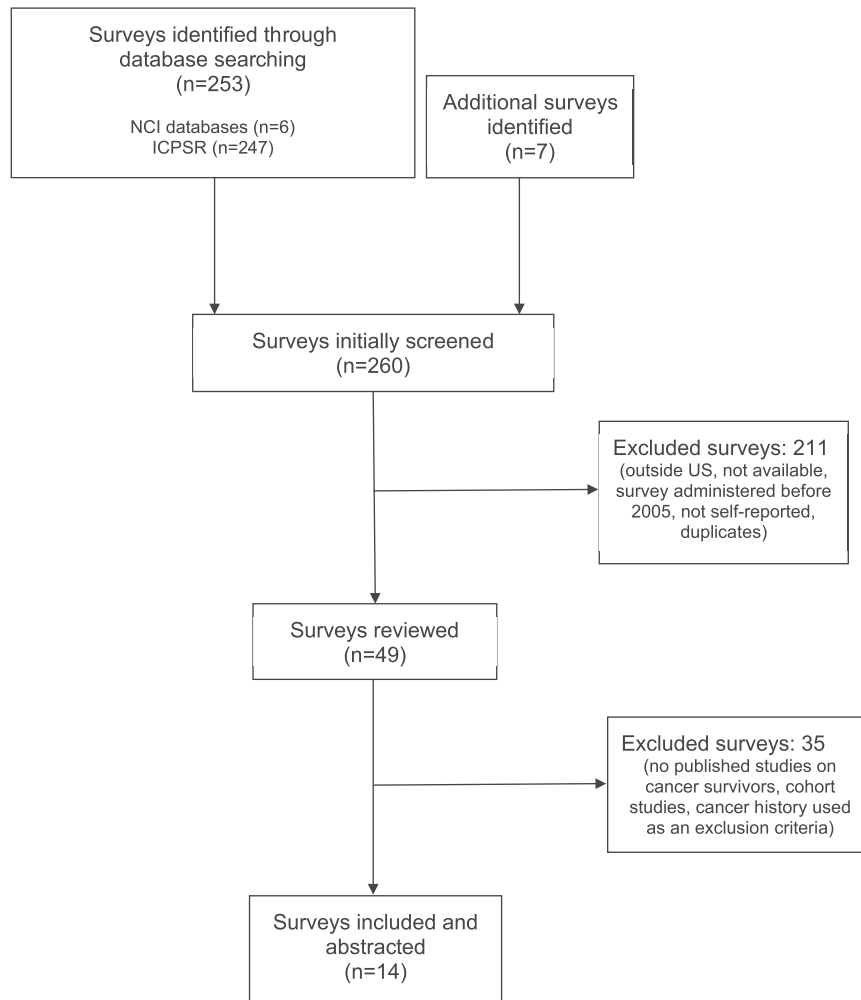
Figure 1. Survey instruments included. ICPSR indicates Inter-University Consortium for Political and Social Research; NCI, National Cancer Institute.

a question asking participants to identify the cancer type by name: "What kind of cancer was it?" or "What type of cancer did you have?" One survey asked that the cancer type be identified by location: "On what part or parts of your body was the cancer found?" All 11 of these surveys included prespecified response options, and 7 also included a free-text response option. The response options to select from included cancer types most commonly diagnosed in adults (eg, bladder, breast, colorectal, prostate, and lung cancer). Rarer cancers were less common. For example, esophageal cancer was a response option in 7 surveys. All except 1 survey did not include a response option for a prior history of childhood cancer; however leukemia, which is the most common cancer of childhood, was included in 8 surveys, and neuroblastoma was included in 1 survey. Ten of the 11 surveys that asked for cancer types also asked

participants to identify multiple cancers in several ways: identify all cancers ever diagnosed, quantify how many different types of cancers, or state if they ever developed a second cancer or were diagnosed with a previous cancer. One survey did not ask for specific cancer types but asked whether this was the first time that the individual had been treated for any type of cancer.

The stage at diagnosis was asked in 2 surveys (14%) with options for cancer stages I through IV. In addition, 3 surveys (21%) asked about a diagnosis of metastatic cancer or if the cancer had spread to other parts of the body. One survey (7%) assessed stage along with options for tumor grades I through IV. The presence of recurrent cancer was assessed in 4 surveys (29%) asking if the cancer had recurred or "had come back."

The majority of the surveys (n = 12; 86%) captured the time from diagnosis by asking the participants either

TABLE 1. Description of Included Surveys (n = 14)

Survey	Year	Population	Cancer Type-Single	Cancer Types-Multiple	Stage	Subtype	Metastatic Cancer	Recurrent Cancer	Time From Dx	Tx
ASCO 2020 National Cancer Opinions Survey	2020	Adults 18 y old or older	X		X		X		X	X
Cancer Experience Registry–A Program of the Cancer Support Community	2019	Adults diagnosed with cancer or caregivers	X	X	X	X	X	X	X	X
CAHPS Cancer Care Survey	2016	Adults diagnosed with cancer	X						X	X
MEPS Cancer Experiences Questionnaire	2017	Adults diagnosed with cancer	X	X	X				X	X
NCCS Cancer Survivorship Survey	2020	Adults diagnosed with cancer	X	X			X	X	X	X
NHIS Cancer Control Supplement	2020	Adults diagnosed with cancer	X	X				X	X	
BRFSS Cancer Survivorship Module	2019	Adults diagnosed with cancer	X	X					X	X
COVID Impact Survey	2020	Adults 18 y old or older	X							
HINTS	2019	Adults 18 y old or older	X	X					X	
MCBS	2020	Medicare beneficiaries	X	X					X	
MHOS	2020	Medicare beneficiaries	X	X						X
National Health and Aging Trends Study	2020	Medicare beneficiaries 65 y old or older	X	X					X	X
NHANES	2018	Adults and children	X	X					X	
FOCUS Survey	2006	Adults diagnosed with cancer	X	X				X	X	X

Abbreviations: ASCO, American Society of Clinical Oncology; BRFSS, Behavioral Risk Factor Surveillance System; CAHPS, Consumer Assessment of Healthcare Providers and Systems; Dx, diagnosis; FOCUS, Follow-Up Care Use Among Survivors; HINTS, Health Information National Trends Survey; MCBS, Medicare Current Beneficiary Survey; MEPS, Medical Expenditure Panel Survey; MHOS, Medicare Health Outcomes Survey; NCCS, National Coalition for Cancer Survivorship; NHANES, National Health and Nutrition Examination Survey; NHIS, National Health Interview Survey; Tx, treatment.

for the age at which they had cancer or for the year of their cancer diagnosis. Three studies included questions about the last time that they received cancer treatment. The response options for time from diagnosis/treatment were mostly (n = 8) open-ended (age or month/year of diagnosis). The remaining 6 surveys had categorical options for reporting the time since diagnosis with discrete increments of time ranging from less than 6 months to more than 20 years ago.

A total of 9 surveys (64%) included items about cancer treatment(s) received (Supporting Table 2), and they varied in the number and types of questions. Six surveys included questions asking whether the participant was currently receiving active treatment, and 5 surveys inquired about treatment types received, such as surgery, chemotherapy, or radiation. Additionally, 2 surveys had questions about the receipt of immunotherapy/targeted therapy. Another survey asked about chemotherapy drugs. Information regarding the type of radiation or surgery was absent. Overall, 6 of the 7 cancer survivor surveys inquired about cancer treatments in comparison with 3 surveys used for the general population.

DISCUSSION

Our study captured the current landscape of questions used to identify and describe cancer survivors in national cross-sectional surveys. We found that most surveys had questions that identified cancer survivors by asking participants whether a doctor or other health professional had ever told them that they had cancer. None of the surveys asked individuals if they were cancer survivors; this is not surprising because this is not a term that all individuals with a history of cancer may recognize or with which they may identify.[9] There was varying information captured on the types of cancer treatments received by individuals or if they were currently on active therapy, and there was even less granular information on cancer stages, subtypes, and metastatic and recurrence statuses. The inability to identify and describe these diverse cancer survivors hinders the study of the experiences and outcomes of these populations and intervention efforts. However, our findings highlight an opportunity to advance cancer survivorship research and clinical care by capturing specific data elements from self-reported survey data that better describe the dynamic and growing population of cancer survivors.

Our findings suggest that asking "Have you ever been told by a health professional that you have cancer?" is a reasonable method for identifying survivors.

TABLE 2. Survey Questions Used to Identify Cancer Survivors (n = 14)

Survey	Question
FOCUS Survey	Have you ever been told by a doctor or other health care professional that you had cancer?
BRFSS Cancer Survivorship Module	Has a doctor, nurse, or other health professional ever told you that you had any of the following? … skin cancer? … any other types of cancer?
MEPS Cancer Experiences Questionnaire	Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?
MHOS	Has a doctor ever told you that you had any cancer (other than skin cancer)?
NHANES	Have you ever been told by a doctor or other health professional that you had cancer or a malignancy (ma-lig-nan-see) of any kind?
NHIS Cancer Control Supplement	Have you ever been told by a doctor or other health professional that you had … cancer or a malignancy of any kind?
CAHPS Cancer Care Survey	Has a doctor, nurse, or other health care professional ever told you that you have cancer?
MCBS	Has a doctor or other health professional [ever] told you that you had any [other] kind of cancer, malignancy, or tumor other than skin cancer?
National Health and Aging Trends Study	We are interested in new health conditions that you have learned about this year. Since the time of the last interview in …, has a doctor told you that you had cancer?
COVID Impact Survey	Has a doctor or other health care provider ever told you that you have any of the following … cancer?
ASCO 2020 National Cancer Opinions Survey	Ever diagnosed with cancer by a health care professional?
NCCS Cancer Survivorship Survey	Have you ever been diagnosed with cancer?
HINTS	Have you ever been diagnosed as having cancer?
Cancer Experience Registry–A Program of the Cancer Support Community	Select statement: I am a person who has been diagnosed with cancer.

Abbreviations: ASCO, American Society of Clinical Oncology; BRFSS, Behavioral Risk Factor Surveillance System; CAHPS, Consumer Assessment of Healthcare Providers and Systems; FOCUS, Follow-Up Care Use Among Survivors; HINTS, Health Information National Trends Survey; MCBS, Medicare Current Beneficiary Survey; MEPS, Medical Expenditure Panel Survey; MHOS, Medicare Health Outcomes Survey; NCCS, National Coalition for Cancer Survivorship; NHANES, National Health and Nutrition Examination Survey; NHIS, National Health Interview Survey.

At the same time, this work emphasizes a role for more nuanced information such as cancer type and stage, time from diagnosis, whether or not they are actively on treatment, and types of treatments. The depth of questions used in cancer survivor cross-sectional surveys was on par with other survey instruments used in cancer survivor cohort studies[21-25] and other population-based cohort studies[26-33] that publish on cancer survivors. According to the overall purpose or main objective of the survey, a single question about cancer history, which was common in surveys of the general population, may be sufficient for the level of detail needed. However, when studies use 1 question to make generalizable observations and/or recommendations, it is critical that cross-sectional surveys further and more precisely characterize survey responders who are cancer survivors. For example, recent national cross-sectional surveys have used self-reported data to understand the effects of coronavirus disease 2019 (COVID-19) on cancer survivors.[34-36] These surveys varied from asking 1 question about cancer history to asking several questions, including questions about metastatic status and being on active treatment. Cancer survivors who are in active treatment versus those who have recently finished treatment or are long-term cancer survivors have different risks of experiencing severe illness and/or death from COVID-19. Without more detailed cancer information, it is impossible to assess the unique and evolving risks of COVID-19 and other medical conditions.

Cancer is a heterogeneous disease. Even distinct anatomical cancer types may necessitate that future surveys add questions that gather detailed cancer-specific information such as cancer type, stage, and molecular subtype. An important reason is that some tumors, such as brain cancers or leukemias, are not classified by stage. Therefore, adding site-specific information such as tumor grade may be valuable. Many surveys in this analysis had a question with response options that encompassed the most common cancer types as options for a prior single cancer and for prior multiple cancers, although not all were inclusive of rarer cancers or childhood cancers. It will be important for future surveys to include questions that can be used to identify the diverse and growing segments of the cancer survivor population, including the 20% of cancer survivors diagnosed with a rare cancer, the 18% of cancer survivors diagnosed with a subsequent cancer, and the more than 420,000 survivors of childhood cancer.[37-39]

Few surveys queried about the metastatic or recurrent status or cancers with an episodic course (eg, multiple myeloma). There are a growing number of individuals with metastatic cancer who are experiencing prolonged survival and who may not identify as a cancer survivor. Information regarding stage IV metastatic cancer at diagnosis can be derived from cancer registries; however, cancers that have metastasized or come back/relapse after not being detected for some time may not be captured by cancer registries and are difficult to assess from health care

claims data.[40] As such, it is critical to include a question that assesses recurrence or the presence of metastatic disease directly from cancer survivors.

Most surveys, though not all, captured the time from diagnosis but not the time from treatment. Six surveys asked individuals if they were currently on active treatment. Because the number of long-term cancer survivors is growing, with 3.1 million living 20 years or more after their diagnosis, the lack of definitional categorization of the time from diagnosis or treatment leaves researchers to conceptualize and report this as they see fit. For example, cancer survivors are often categorized in the literature according to the time from diagnosis with cutoffs such as 5-year survival.[1,2] This method does not take into account other factors such as treatment length that vary by cancer type and stage and may ultimately affect cancer-related experiences and outcomes.

Cancer treatment is typically multimodal, including surgery, chemotherapy, radiation, hormonal therapy, immunotherapy, and/or targeted therapy. In this analysis, all but 1 of the cancer survivor cross-sectional surveys included questions about specific types of treatments received. Although our analysis did not include cohort studies focusing on cancer survivors, cancer survivor cross-sectional surveys appear to be more inclusive of treatment information in comparison with findings from an environmental scan of cancer survivor epidemiology cohort studies.[41] Without a comprehensive assessment of the receipt and completion of different types of treatments, it is impossible to identify associated treatment-related adverse effects (acute, late, and long-term).

It is important to recognize that diagnosis and treatment information may not be uniformly recalled by all individuals; this may vary on the basis of the length of time between treatment and survey administration. Diagnosis information such as stage, grade, and molecular subtype has not been thoroughly assessed. Three studies suggest that the accuracy of recalling cancer stage was moderate (59%) to high (91%) among breast cancer survivors, whereas the molecular subtype was moderately recalled (39%-94%), and the tumor grade was least accurately recalled (33%).[42-44] Some evidence demonstrates that detailed treatment information is recalled by cancer survivors but varies by cancer type and other factors. For example, the accuracy of treatments received has been found to be high among breast cancer survivors,[42,43,45,46] including low-income, minority, and older individuals.[47,48] Even among adult survivors of childhood cancer, the accuracy for reporting their treatment history was 94% for chemotherapy and 89% for radiation (including 70% who

recalled the radiation site).[49] Other variables, such as specific chemotherapy medication names, may be recalled less often.[44,45,49] Nevertheless, reliance on self-report for specific cancer treatment details should be considered when appropriate and, if at all possible, be supplemented with medical records. However, missing and inconsistent documentation of cancer diagnoses and treatment histories in electronic health records remains problematic, with Hoopes and colleagues[50] finding only moderate agreement ($\kappa = 0.54$) between cancer registries and electronic health record documentation of cancer.

To advance cancer survivorship research, future research using self-reported survey data should consider including questions that capture and describe the dynamic, heterogeneous population of cancer survivors. First, we need to ask questions that are inclusive of all cancer types, stages, and molecular subtypes when appropriate. Second, we need to ask questions and/or standardize the analysis of the time from diagnosis or treatment to identify cancer survivors in meaningful phases or categories of treatment and survivorship, including those who are living with metastatic and/or recurrent cancer. Third, we need to develop questions that ask about multimodal treatments received and the intent of treatment, including curative and palliative therapies. As precision medicine advances and new targeted therapies are made available, surveys will need to adapt to prospectively capture this information. Lastly and importantly, this work should be done in partnership with cancer survivors and advocacy groups to ensure that questions, response items, and interpretations of analyses make sense to the target population and capture relevant information not only for the researchers but also for cancer survivors.

We acknowledge the limitations of this study. We may not have captured potentially eligible surveys outside our search strategy and criteria. Furthermore, when more than 1 version was available, only the most recent survey version was abstracted, so changes over time were not assessed. We did not assess the intended objective of the overall study design, the survey instruments, or the analytic plan, including whether the survey linked to medical records, tumor registries, or other means of validation. We also examined only surveys written in English and may not have identified surveys in other languages (eg, Spanish) that are used in US studies. Lastly, we reviewed the surveys directly and did not examine the reported psychometric properties and/or prior validation of the surveys. Despite these limitations, our detailed approach to data collection, including the identification of surveys used nationally, by states, in defined communities, and by patient advocacy

organizations, as well as the rigorous abstraction methodology allowed us to capture the breadth of the available data. We believe that our study achieved its goal of synthesizing the current scope of survey questions to see how they identify and describe cancer survivors.

In conclusion, our study found that asking individuals directly about a cancer diagnosis is a reasonable method for identifying cancer survivors, whereas opportunities to expand survey questions to describe more nuanced aspects of survivorship would advance the field. The lack of a current standard method for assessing self-reported cancer history may limit the ability to distinguish among potentially important subgroups of survivors. Cross-sectional surveys have the potential to help fill in the gaps when data collection in future studies is expanded to capture the dynamic, heterogenous, and growing cancer survivor population.

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AUTHOR CONTRIBUTIONS
Michelle Doose: Conceptualization, data curation, formal analysis, investigation, methodology, project administration, writing–original draft, and writing–review and editing. **Michelle A. Mollica:** Conceptualization, methodology, writing–original draft, and writing–review and editing. **Deanna J. Attai:** Writing–original draft and writing–review and editing. **Shelley Fuld Nasso:** Writing–original draft and writing–review and editing. **Joanne W. Elena:** Writing–original draft and writing–review and editing. **Paul B. Jacobsen:** Writing–original draft and writing–review and editing. **Emily S. Tonorezos:** Methodology, writing–original draft, and writing–review and editing. **Larissa Nekhlyudov:** Conceptualization, data curation, formal analysis, investigation, methodology, validation, writing–original draft, and writing–review and editing.

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