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Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: implications for the Affordable Care Act

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Abstract

Introduction—Childhood cancer survivors face long-term health consequences, and comprehensive health insurance is critical. However, childhood cancer survivors may face barriers

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in accessing medical services due to being uninsured or underinsured. Little is known about the quality of survivors' health insurance coverage, and improving health insurance within the context of changes mandated by the 2010 Affordable Care Act requires understanding survivors' coverage. The current study explored adult childhood cancer survivors' quality of health insurance coverage.

Methods—From 9/09 to 2/10, we conducted in-depth, semi-structured qualitative interviews with 39 adult participants from the Childhood Cancer Survivor Study, a cohort of 5-year survivors of cancers diagnosed before age 21. Interviews were recorded and transcribed; content analyses were conducted by two coders (kappa00.88) using NVivo 8.

Results—Most insured survivors reported satisfaction with the quality of their coverage; however, they expressed low expectations. Almost half reported annual out-of-pocket costs exceeding $2,000, yet most felt fortunate to simply have coverage. One third of insured survivors had difficulty obtaining coverage, and many had difficulties understanding how to utilize it. Most uninsured survivors minimized their need for care. Worry about future health care costs seemed inevitable among insured and uninsured survivors. Almost all participants lacked knowledge about existing health insurance-related laws.

Conclusions and implications for cancer survivors—Insured survivors had low coverage expectations, and uninsured survivors avoided care. Childhood cancer survivors will likely benefit from assistance in how to access and utilize the new health care reform provisions (e.g., Medicaid expansion, expansion of parents' insurance, and mandatory primary care coverage).

Keywords

Childhood cancer; Childhood Cancer Survivor Study; Health insurance; Affordable Care Act

Introduction

With the 5-year survival rate for childhood cancer survivors at 79 % [1] and the 10-year survival rate reaching almost 70 % [2], childhood cancer survivors are a growing population. In 2005, there were over 325,000 childhood cancer survivors in the USA [3]. Many childhood cancer survivors face long-term health consequences from their cancer and treatment, such as subsequent cancers or severe chronic health conditions [4–6]. Although mortality due to recurrence or primary disease progression is decreasing for childhood cancer survivors, mortality due to treatment-related effects (e.g., subsequent neoplasms, pulmonary or cardiac complications) is increasing [7]. Childhood cancer survivors need close medical surveillance throughout life to mitigate late effects from their cancer treatment [8].

However, childhood cancer survivors may face barriers in accessing primary care and other medical services due to being uninsured or underinsured. Previous research has found that childhood cancer survivors are more likely than unaffected individuals to be unemployed [9] and uninsured [10]. In particular, among survivors, lack of coverage is associated with lower incidence of ongoing medical care, cancer-related medical visits, decreased utilization of dental services, and lower rates of cancer screening [12, 13]. Furthermore, childhood cancer survivors who have coverage are less likely than their siblings to have employer-sponsored insurance and are more likely to report difficulty obtaining insurance coverage [10], suggesting that they may face barriers to quality insurance coverage or stability [13].

The 2010 Affordable Care Act (ACA) is intended to ensure access to affordable health care; it provides several avenues to coverage for uninsured individuals and may ease cost burdens for those who have coverage [14]. This legislation is particularly important since recent years have brought declining rates in the extent of coverage and increased premiums in employer-sponsored health insurance [15]. In addition, higher copayments and deductibles have increasingly shifted costs to individuals. Childhood cancer survivors may benefit from many of the ACA’s provisions, including Medicaid expansion, expansion of parents’ insurance coverage to 26 years of age, mandatory primary care visit coverage requirements, and required coverage for US Preventive Services Task Force (USPSTF) recommended preventive care [16]. However, it is unknown how the ACA may help this population [17].

This report summarizes information obtained through interviews to elicit information prior to development of a national survey to examine the quality of health insurance coverage among adult survivors of childhood cancer. These interviews were conducted prior to the passing of the ACA and may provide a baseline exploration to anticipate how currently insured and uninsured childhood cancer survivors might fare under the current ACA. We explored survivors’ (1) satisfaction with insurance coverage, (2) experiences obtaining and using their insurance, (3) perspectives on coverage preferences and concerns, and (4) knowledge of health insurance-related legislation.

Methods

Interviews with cancer survivors were conducted as part of a national study to assess the quality of coverage among childhood cancer survivors. All procedures were approved by the Institutional review boards of St. Jude Children’s Research Hospital and the Massachusetts General Hospital/Partners HealthCare. In accordance with Consolidated Criteria for Reporting Qualitative Research guidelines, we describe our research team, study design, data analysis, and findings [18].

Participants and recruitment

Childhood Cancer Survivor Study (CCSS) participants who had completed the 2007 survey (approximately 9,600 participants) were eligible to be selected for interviews. CCSS is a multi-institutional retrospective cohort with longitudinal follow-up, funded by the National Cancer Institute [19–21]. CCSS participants were diagnosed between 1970 and 1986, before 21 years of age, with leukemia, central nervous system malignancies, Hodgkin’s lymphoma, non-Hodgkin’s lymphoma, kidney tumor, neuroblastoma, soft tissue sarcoma, or bone cancer and survived at least 5 years. Eligible survivors were identified at 25 participating centers in the USA, yielding a retrospectively ascertained cohort of adult childhood cancer survivors. Using random selection, stratifying by age (≤30 and >30 years) and health insurance status (uninsured and insured) on the 2007 follow-up survey [10], we sent recruitment letters to 95 participants and were able to contact 48; 6 were ineligible, 3 refused, and 39 participated (39/42; 93 % acceptance rate). Sociodemographic characteristics were obtained from the follow-up survey. We recruited participants until thematic saturation (the point at which no new themes emerged) was achieved [22]. From September 2009 to February 2010, in-depth interviews were conducted via telephone with 39 participants. Interviews lasted approximately 30 min. Participants received a $20 gift card.

Data collection and analysis

A semistructured interview guide was developed. Insured survivors were asked about (1) satisfaction with coverage and (2) difficulties obtaining and using coverage. Uninsured survivors were asked about their experiences of being uninsured. All participants were asked about (1) plan preferences, (2) coverage-related concerns, and (3) knowledge of health insurance-related legislation. Participants were asked specific questions based on insurance status. For example, insured participants were asked about their concerns regarding their current insurance costs, coverage, and access (e.g., “Do you worry that you’ll need something that isn’t covered in your current plan?”). Uninsured participants were asked about their concerns about not having coverage (e.g., “Do you worry that you’ll need something that you do not have coverage for?”) The guide was pilot tested on eight childhood cancer survivors who received their treatment at Massachusetts General Hospital and was modified based on feedback. One CCSS interviewer was trained by the PI and conducted the telephone interviews.

Interviews were recorded and transcribed; content analyses were conducted [23]. Two members of the research team (JP and AK) coded all data independently using NVivo 8. At each phase of the iterative analysis process, the two coders compared their results to confirm intercoder reliability (final kappa00.88), resolving discrepancies through discussion with the PI (EP) and comparison of the raw data. All analyses compared insured and uninsured participants.

Results

Sample characteristics

Thirty-nine survivors participated in telephone interviews. Twenty-five participants were insured (3 had Medicaid and 1 had Medicare), and 14 survivors were uninsured (Table 1). Over half of participants were under 30 years of age, and 74 % were white, non-Hispanic. Forty-two percent of uninsured participants and 27 % of privately insured participants had annual household incomes of <$20,000. Insured survivors were typically insured through their employers or spouses’ employers and often reported being consistently insured. Most uninsured survivors were employed, but had not had coverage for more than 3 years; most had been insured previously, but lost coverage due to job transitions or aging out of their parents’ plans.

Insured participants' satisfaction with coverage

Overall satisfaction with current coverage was high

All participants were asked about their satisfaction with their current coverage's access to care, services covered, and cost. Almost all insured survivors expressed satisfaction, albeit with nonspecific descriptions, with their current coverage's access to care and services currently covered. However, there seemed to be a low bar for coverage satisfaction regarding the cost of their insurance. One survivor explained: "I'm glad I have insurance," but then admitted, "It could be better. It gets more expensive every year and has less coverage."

Moreover, this low bar for satisfaction occurred because survivors believed that affording coverage on their own would be difficult, and so they were willing to pay higher out of pocket costs from premiums, co-pays and deductibles. This was described as: "The deductibles I really have no problems with because they're tolerable, it's better than when it was on my parents' insurance. Their co-pays and stuff were higher so I mean this (plan) is more accommodating, but yet it could be better especially at seeing as how much…I pay in each month for monthly premium to them."

Areas of dissatisfaction

Despite the fact that most insured participants reported that they were satisfied with services offered, more than half of the insured survivors were dissatisfied with high costs (i.e., deductibles, copays and premiums). When asked how much they paid in out-of-pocket costs for health care in the past year, almost half of insured survivors exceeded $2,000 in out-of-pocket costs, which is often used as an indicator for underinsurance. One survivor explained: "We have a huge deductible because we're paying, you know, like a thousand a month…. But that's all we could do, we both have pre-existing conditions."

Some survivors expressed dissatisfaction about service access, specifically not having a choice of provider and difficulties getting appointments or finding providers to accept their coverage. A lack of auxiliary services (dental, mental health, and vision) was mentioned by eight survivors. A few were frustrated that their insurance did not cover survivor-specific cancer screening services. One woman explained: "Being a cancer survivor a mammogram is suggested for me at this age. But because I'm not of healthcare suggested age, it's not covered."

Insured participants' difficulties with obtaining and utilizing coverage

Obtaining coverage

One third of insured survivors reported that they had been denied health insurance coverage in the past because of their health history; they eventually obtained coverage through another plan or found employment that offered group insurance. Many insured survivors described the process of obtaining coverage as frustrating. One survivor said: "I was so just kind of flabbergasted when I went to try and get insurance on my own…I thought it would be a simple easy experience and I was severely wrong…"

Utilizing coverage

Many insured survivors had difficulties understanding how to utilize their coverage. One survivor explained: "…At this point I don't even know what is covered because I tried reading the booklet and of course I don't understand all the language in it." Another survivor admitted: "That's what's always been a little confusing in this particular plan is that I'm not really sure who we can see and who we can't see." Other survivors discussed displeasure in the administrative barriers or access available in utilizing their coverage.

Uninsured participants' attitudes about not having coverage

Avoiding care

Most uninsured survivors received minimal care. One survivor explained: "I usually avoid going to the hospital for anything." Many attributed their lack of health care to being uninsured, but few were concerned about not having coverage. One third of uninsured survivors did acknowledge that it was a burden to not have coverage. One uninsured survivor acknowledged: "You know you probably should go to the doctor, but you know its $300–$400 a visit you don't have…plus your whole weeks pay."

Medicaid barriers

Most uninsured survivors had been uninsured for many years, yet knew very little about how to access public (e.g., Medicaid) health insurance. Several believed they made too much money to qualify or had previously applied and been denied.

Participants' coverage preferences

Survivor-specific preferences

Both insured and uninsured survivors were asked what the most important components survivors should have in a health insurance plan. Most participants had difficulty articulating the types of services and cost options they needed, often asserting that it was just important for survivors to have any coverage or access to treatment. A handful specifically stated they never thought about survivor-specific insurance needs. One survivor mused: "Boy, you got me. I don't ever really think about it." However, routine care, physician choice, and protection from inflated costs due to pre-existing conditions were the most common preference responses; for several interviewees, their status as a survivor explicitly influenced their coverage preferences.

Emphasis on primary care services and preventive care

Both uninsured and insured survivors prioritized the need for coverage for routine care services: "Just a good primary care doctor" and preventive care, such as cancer-specific screening to detect cancer recurrence or new cancers. One survivor suggested: "…A plan that allows (survivors) to get follow-up treatment just to make sure, you know, the cancer doesn't come back…." Another survivor expressed his frustration with the lack of preventive services offered by his plan: "I think it's ridiculous that the plan that I have now only covers me if I get really sick but doesn't cover me if I just want to maintain my health."

Physician choice and continuity of care

Physician choice, particularly being able to maintain the same doctors, was frequently mentioned. One survivor noted: “I think being able to go to any doctor that you need to be going to is important.” For some survivors, this was particularly important due to their previous cancer history. One male survivor said he liked that: “I’m able to see the doctor that I want to see especially since I was…a cancer patient.” Others prioritized having access to specialists. One survivor explained: “Well the only thing that I pretty much look for is a broad availability of the specialist I need.”

Affordable care without higher costs due to pre-existing conditions

Some survivors attributed the high cost of their health insurance to their previous cancer history. Participants expressed desires for care to be affordable without a trade-off in quality. Half of insured survivors emphasized the importance of having no exclusions/denials due to preexisting conditions. One participant expressed: “I don’t think (survivors) should be discriminated against for preexisting conditions.” A few uninsured survivors described previous circumstances where they were denied coverage due to their health history.

Participants’ coverage concerns

Inability to afford coverage and loss of coverage in the future

Many insured survivors worried about coverage cost increases and that costs would eventually become burdensome. Insured survivors also worried about future loss of coverage. One survivor explained: “Next year I have to have so many hours to have insurance…I may not have enough hours that are worked, so that’s what I’m concerned about.” An issue that was specific to publically insured survivors was concern about gaps in coverage due to eligibility reevaluation. One described his concern: “I worry about [Social Security] coming back and telling me ‘No you’re not disabled you’re able to go back into the work force,’ which my doctors have told me that I will never be able….” Another publically insured survivor experienced intermittent coverage because her eligibility was re-determined two times a year: “They seem to take their good old time in getting back to you and usually by the time they get back to you you’ve already lost coverage for like a month. So you just like pray that you or your kids don’t get sick.”

Lack of preventive care & future health care and coverage needs

Most uninsured survivors did not worry about their current uninsured status and/or avoided thinking about it. One survivor stated: “I don’t think of it. It’s just not something that I try to worry about.” However, many uninsured survivors acknowledged concerns about their future health and ability to obtain health insurance coverage if needed. One uninsured survivor reported being worried about not getting the preventive care needed: “I also worry about cancer because I know I’m more likely to have cancer again than other people…I would like to be able to go to the doctor and afford it and you know, get a check-up once a year at least.” Similar to the insured, many uninsured survivors worried about a future health problem that would require expensive care that they could not afford. One uninsured survivor acknowledged: “Yeah it does concern me that, if something happens…. Nobody’s going to give me insurance. That’s a pre-existing condition and a million dollars worth of bills.”

Participants’ knowledge and beliefs about health-insurance related laws

Lack of knowledge about laws

There was a pervasive lack of knowledge about current health insurance-related legislation. Few survivors knew about the Americans with Disabilities Act. (ADA) Approximately half of participants were aware of Consolidated Omnibus Budget Reconciliation Act (COBRA) and Family and Medical Leave Act (FMLA). Some had obtained COBRA to continue coverage after leaving a job, while others had accessed the benefits available under the FMLA when taking maternity or medical leave. Several uninsured and insured survivors had opted not to take COBRA during past job transitions due to the high cost. As one survivor described: “I quit my job and got another job so I tried to extend my insurance with COBRA, the out-of-pocket expense was just astronomical. I don’t know if that was specifically the reason why…because I am a high risk person.” Although these interviews were conducted during the national debate of the health care reform, it was only mentioned by one survivor.

Beliefs about protections

When asked about laws that might protect survivors from health insurance discrimination, survivors’ attitudes were often angry or defeated. One survivor exclaimed: “Everything discriminates against me. I had been clean for 20, over 20 years and everything is…they charge you more for. Another participant reported: I’d always have to pay like ten times as much as anyone else would have.” Several survivors were afraid that their medical records could be retroactively accessed or their current conditions could be used to deny them health insurance coverage.

Discussion

We interviewed 39 childhood cancer survivors about their perceptions and knowledge of health insurance coverage. This is the first published study to explore childhood survivors’ attitudes about the quality of their coverage, the impact of not having coverage, and coverage concerns. In addition, this is the first study that describes what childhood cancer survivors know about their coverage plans and health insurance coverage-related protections. The ACA will have widespread impact for the childhood cancer population, improving their access to primary care services; we summarize the implications of these findings on the potential benefits and limitations of this law.

Overall, insured survivors seemed satisfied with their health insurance coverage, despite often describing high costs. Coverage cost was the most salient area of dissatisfaction among insured survivors and the most common barrier to coverage among uninsured survivors. These satisfaction findings are similar to findings from a recent national survey, which showed that 80–91 % of Americans were satisfied with their quality of medical care, but that only 61 % were satisfied with its cost [24, 25].

The insured survivors were hesitant to complain about *coverage costs*; rather, they expressed being grateful to simply have coverage. This hesitation could be due to the fact that many survivors had difficulty obtaining coverage and understood that purchasing insurance on their own would be untenable. Out-of pocket costs seemed particularly burdensome. More than half of insured participants reported paying over $2,000 out-of-pocket per year for medical care, compared to a recent survey where 41 % of chronically ill individuals reported that they spent more than $1,000 out of pocket [11]. There are provisions in the ACA intended to help with the affordability of insurance (e.g., a required review process for insurance companies enacting a rate increase), which may assist with childhood cancer survivors' coverage cost burdens. However, state-run exchange plans will likely save on premium costs by limiting networks; this could create discontinuity in care, particularly for survivors who have long established relationships with a primary care provider. Additionally, survivors who use a high level of medical care services will continue to face high out of pocket costs, still affecting their use of primary care and other services.

Worry about future health care costs seemed inevitable among both insured and uninsured survivors. Insured participants fear rate increases, potential loss of insurance, and inability to regain insurance once lost. Although uninsured participants seemed to minimize their current health care needs, they expressed concerns about their inability to gain insurance if needed. Underlying these future concerns was a fear that "something bad" would happen in the future for which costs would be prohibitive, consistent with the Damocles syndrome with which childhood cancer survivors are associated [26]. That is, these survivors are in a state of long-term uncertainty regarding catastrophic medical care needs likened to the mythical figure who was forced to live under a suspended sword.

Survivors expressed concerns that echoed American perspectives on coverage protections for a chronic illness. When Americans were asked what their level of concern would be if they were to have a serious illness in the future, 64 % reported that they were worried they would not be able to pay their medical bills [27]. Given that this is a genuine concern for survivors, it is important that there are protections in the ACA that may allay these fears. As of 2010, health insurance companies can no longer rescind a policy once someone gets sick, nor can they impose lifetime limits on coverage. Beginning 2014, health insurance companies will no longer be able to deny coverage to adults with preexisting conditions.

Uninsured survivors seemed to have accepted not being able to afford and thus not having coverage. It is also unclear how uninsured survivors will respond to the ACA's requirement of minimum essential coverage (beginning in 2014), or if they will pursue getting coverage through state-run insurance exchanges (that offer subsidies that lower premiums as needed) or high risk pools (which may be under-funded and unaffordable with annual out-of-pocket caps at $5,950 for individuals) [28]. Uninsured participants might now be eligible for Medicaid under the ACA (parents or adults without dependent children with incomes up to 133 % of the federal poverty level). However, it is uncertain if survivors would be motivated to get Medicaid coverage, once eligible, given that many reported that they did not know how to obtain Medicaid coverage.

Other aspects of the ACA could clearly benefit this population. First, many uninsured participants reportedly lost their coverage when they aged out of their parents' insurance; the provision requiring insurers to allow children to remain on their parents policies until age 26 could be very helpful. Second, participants' expressed preferences for coordinated care could be met by the ACA's state Medicaid option to permit individuals with a chronic condition to select a medical home (e.g., community health center, comprehensive primary care clinic) that would be responsible for all patient care. Third, participants' expressed emphasis on preventive care matches the ACA's priority of access to preventive services, which is an area of needed improvement as many childhood cancer survivors are non-adherent to recommended risk-based care [13, 29–32]. However, survivors might need services (e.g., mammography before age 50), which are not recommended by the USPSTF guidelines. This indicates a need to educate survivors to solicit support, from their oncologists and survivorship follow-up programs, to assist in obtaining coverage for survivorship-plan recommendations, such as specific cancer screening services.

Survivors' utilization of the ACA benefits could be constrained by psychological and knowledge barriers. Participants expressed both pessimism and discouragement in being able to obtain affordable coverage and access helpful protections or resources; this sense of learned helplessness might impede their ability to pursue assistance. There was an admitted lack of knowledge about current coverage and legislative protections; the sense of frustration expressed by participants, when asked about laws that might protect them, might explain their disengagement and avoidance on these matters. Health insurance exchanges, intended to simplify and standardize health insurance options, and patient navigators, who will assist people enrolling onto the state plans, could help survivors demystify their insurance options.

Although these interviews were conducted during late 2009 through early 2010–when health insurance reform was undergoing national debate—few survivors mentioned health care reform. This suggests that many of the new reform initiatives might not be readily utilized. However, almost all participants said that they would be interested in an educational program to learn how to obtain and better understand coverage and legal protections.

These data are strengthened by use of an established national childhood survivor cohort, but there are limitations. First, these data were collected just prior to the passing of the ACA, and we were not able to directly ask participants about their impressions of this reform. However, our findings describe participants' perceptions and experiences prior to health care reform, from which we can assess post-reform changes. Our next steps include a quantitative examination of survivors' and sibling controls' impressions and knowledge about their coverage, following the passing of the ACA. Second, we had a small representation of participants who received coverage through Medicaid, so we were not able to compare findings among participants with private coverage versus participants with Medicaid coverage. Third, these data are drawn from a cohort of survivors who were treated only at tertiary cancer centers and, therefore, may not be representative of the general population of childhood cancer survivors. In addition, the household income reported by study participants was lower than the household income reported in the CCSS cohort.

In summary, although ACA provisions address childhood cancer survivors' health care concerns and needs, there may be limitations to the provisions and anticipated barriers to its uptake. For the ACA provisions to be beneficial, childhood cancer survivors must access insurance and utilize services, particularly routine care and preventive services, and will likely need help to do so. Moreover, as insurance expansion provides survivors with fewer cost barriers to primary care services and other care, physicians should be aware of the insurance and service needs of this population. To maximize the intended benefit of health care reform for childhood cancer survivors, future survivor-targeted educational programs are needed and must include information on costs, access, and utilization.

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Table 1

Participant characteristics

	Insured (*N*=25) Number of patients (Percent)	**Uninsured (*N*=14) Number of patients (Percent)**	**Total (*N*=39) Number of patients (Percent)**
Age at interview (years)			
≤30	12(48)	9(64)	21(54)
>30	13(52)	5(36)	18(46)
Age at diagnosis (years)			
0–4	16(64)	8(57)	24(62)
5–20	9(36)	6(43)	15(38)
Gender			
Male	13(52)	7(50)	20(51)
Female	12(48)	7(50)	19(49)
Race			
White, not Hispanic	20(80)	9(64)	29(74)
Black, not Hispanic	1(4)	2(14)	3(8)
Hispanic	1(4)	1(7)	2(5)
Other	3(12)	2(14)	5(13)
Cancer diagnosis			
Leukemia	13(52)	5(36)	18(46)
Central nervous system	3(12)	–	3(8)
Wilms (kidney) tumor	3(12)	4(29)	7(18)
Non-Hodgkin’s lymphoma	1(4)	1(7)	2(5)
Bone	1(4)	1(7)	2(5)
Hodgkin’s lymphoma	2(8)	1(7)	3(8)
Neuroblastoma	1(4)	2(14)	3(8)
Soft tissue sarcoma	1(4)	–	1(3)
Education[a,b]			
<College	11(48)	9(64)	20(54)
≥College graduate	12(52)	5(36)	17(46)
Household income[b,c]			
<$20,000	9(39)	5(42)	14(40)
$20,000–39,999	4(17)	3(25)	7(20)
$40,000–59,999	3(13)	1(8)	4(11)
$60,000–79,999	2(9)	1(8)	3(9)
$80,000–99,999	2(9)	1(8)	3(9)
Over $100,000	3(13)	1(8)	4(11)
Marital status[b]			
Single (never married)	11(44)	7(50)	18(46)
Married, living as married	12(48)	7(50)	19(49)
Divorced	2(8)	–	2(5)
SMN[*]/recurrence[b]			

	Insured (*N*=25) **Number of patients (Percent)**	**Uninsured (*N*=14)** **Number of patients (Percent)**	**Total (*N*=39)** **Number of patients (Percent)**
Yes	4(16)	3(21)	7(18)
No	21(84)	11(79)	32(82)
Insurance type			
Private	21(84)	–	21(54)
Public	4(16)	–	4(10)

[a] Missing education for two insured survivors

[b] Data from 2007 follow-up survey

[c] Missing household income from two insured survivors and two uninsured survivors

[*] Second malignant neoplasms