Summary and Chartpack

The USA Today/Kaiser Family Foundation/Harvard School of Public Health

National Survey of Households Affected by Cancer

November 2006
Methodology

The USA Today/Kaiser Family Foundation/Harvard School of Public Health Survey Project is a three-way partnership. USA Today, Kaiser, and the Harvard School of Public Health jointly design and analyze surveys examining health care issues.

Representatives of USA Today, The Henry J. Kaiser Family Foundation, and the Harvard School of Public Health worked together to develop the survey questionnaire and analyze the results. USA Today retains editorial control over the content published by the paper. The project team included Jim Norman, USA Today polling editor; Drew E. Altman, president of the Kaiser Family Foundation, Mollyann Brodie, vice president and director of public opinion and media research, and Liz Hamel, associate director of public opinion and media research; and Robert J. Blendon, professor of health policy and political analysis at the Harvard School of Public Health and the John F. Kennedy School of Government, and John M. Benson, managing director of the Harvard Opinion Research Program in the Harvard School of Public Health.

The National Survey of Households Affected by Cancer is a nationally representative survey of 930 adults ages 18 years and older who say they, or another family member in their household, have been diagnosed with or treated for cancer in the past five years (excluding non-melanoma skin cancer). The survey was conducted by telephone between August 1 – September 14, 2006. Telephone interviews were conducted by ICR/International Communications Research of Media, PA.

The margin of sampling error for the survey is plus or minus 3.6 percentage points for total respondents. For results based on smaller subsets of respondents the margin of sampling error is higher. Sampling error is only one of many potential sources of error in this or any other public opinion poll.

Values less than 0.5% are indicated by an asterisk (*). “Vol.” indicates that a response was volunteered by respondent, not an explicitly offered choice. Percentages may not always add up to 100% due to rounding.

A note about how data are reported in this document: The people interviewed for this survey included both people who currently have cancer or have had cancer themselves, as well as the family members of those who have/had cancer. Questions about the cancer experience, treatments, health insurance status, etc. were asked about the person with cancer specifically. For example, if the respondent was the person with cancer, the question was “During the course of your cancer treatment, did you receive conflicting information about your cancer from different doctors, or not?” – if the respondent was a family member, the question was “During the course of your (mother)’s cancer treatment, did she receive conflicting information about her cancer from different doctors, or not?” For ease of reporting, we present the findings as if they were reported by the person with cancer (i.e. X% say they received conflicting information from different doctors).
KEY FINDINGS

Ten percent of Americans say that they or another family member in their household has been diagnosed or treated for cancer in the past five years. Our purpose in surveying these people was to take a broad look at the problems – including challenges related to dealing with health care costs and health insurance – faced by people who have experienced a major illness – in this case, cancer. [For a basic description of the sample according to type of cancer, time since diagnosis, and prognosis given, see Charts 1-4.]

SECTION 1: The financial impacts of cancer on families

Cancer can be a big financial burden on families, particularly those with lower incomes, and those facing cancer without health insurance. Many have to dip into (or deplete) their savings to pay for cancer treatments, and some have trouble affording basic necessities like food and housing while paying for cancer care.

• The cost of treating cancer is a burden for most families who are affected by the disease. Nearly half of people whose families have been affected by cancer say the costs of cancer care were a burden on their family, including one in six who say such costs were a MAJOR burden (Chart 5).
• In addition, significant minorities report some serious consequences of the financial costs of dealing with cancer (Chart 7).
  • One quarter say they used up all or most of their savings, and one in ten report being unable to pay for basic necessities like food, heat, and housing
  • Borrowing: 13% say they borrowed money from relatives, 11% sought the aid of a charity or public assistance, and 7% borrowed money or took out another mortgage on their home
  • 13% say they were contacted by a collection agency, and 3% declared bankruptcy
• In some cases, cost can be a factor that affects the treatment decisions of people with cancer: one in twelve (8%) say they delayed or did not to get care for cancer because of the cost, and 4% say they chose one cancer treatment over another because of the cost (Chart 9).
SECTION 1: The financial impacts of cancer on families (Continued)

• Most people (95%) report being covered by insurance during their cancer treatment. However, even among those with insurance, cost and billing issues are often a problem. Among those with insurance, nearly one in four say their plan paid less than expected for a bill, one in eight say they were surprised to find out their plan wouldn’t pay anything for a bill they thought was covered, one in ten reached the limit of what their insurance would pay for cancer treatment, and one in twelve were turned away or unable to get a specific type of treatment because of insurance issues (Chart 10).

• Cancer can also be an issue that makes it difficult for people to get and keep insurance. One in ten (11%) say they were unable to buy health insurance because of having cancer, and 6% say they lost their health insurance as a result of having cancer. Eight percent report trying to purchase life insurance and being unable to do so (Chart 11).

Who is hardest hit by costs?

• Not surprisingly, people facing cancer without health insurance face a particularly large burden when it comes to the financial impacts of cancer. Among those who were uninsured at the time of interview or at some point during their cancer treatment, more than two-thirds (68%) say the costs associated with cancer treatments were a burden on their families, including nearly half who say they were a MAJOR burden (Chart 6).

  • Nearly half (46%) of people facing cancer without health insurance say they used up all or most of their savings to pay for treatments, and more than four in ten say they were unable to pay for basic necessities (41%). More than a third (34%) were contacted by a collection agency (Chart 8). More than a quarter (27%) say they delayed care or decided not to get treatment for their cancer because of the cost (Chart 9).

  • In addition to those without health insurance, the financial impact of cancer is also felt more acutely by younger people and those with lower incomes (Chart 6).
SECTION 2: The impacts of cancer on home and work life

*Cancer affects families in many ways, not just health-related. Many report stress and strain, including health effects on family members besides the person with cancer. Cancer also has various impacts on work life, both for the person diagnosed with cancer and their family members.*

**Impacts on home life:**

- The psychological stress of dealing with cancer is felt by many families. One third say that the cancer experience caused someone in their household to have emotional or psychological problems, and one quarter say the experience caused severe strains with other family members (Chart 12).

- Not surprisingly, the emotional strain is particularly acute when a family member has passed away from cancer – six in ten in this group say the experience caused emotional or psychological problems for someone in the family, and more than four in ten say it resulted in severe family strains. And among those whose cancer is in remission or has been cured, those who have lingering physical limitations due to their cancer or treatments are more likely than those who have been able to resume all their normal activities to say that the experience resulted in emotional or psychological problems (44% vs. 15%) or severe strains in the family (31% vs. 14%). Emotional strain and family problems are also more commonly reported among families where the person facing cancer was relatively young (48% vs. 23% for emotional/psychological problems and 41% vs. 17% for family strain in ages 18-49 vs. ages 65+) (Charts 13 & 14).

- A smaller, but still important share – 10% – say the experience with cancer caused someone else in their household (besides the person with cancer) to have health problems (Chart 12). Again, these health problems were most common among family members of those facing the more serious cases of cancer – including 21% in families where someone passed away from cancer, and the same share in families who were told the cancer was likely to be fatal.
Section 2: The impacts of cancer on home and work life (Continued)

Impacts on work life:

• More than four in ten (44%) people in the survey say that the person with cancer was employed at the time they were diagnosed. The vast majority say their employer treated them well during their experience with cancer, including three-quarters who say they were treated “very well” (Chart 15).

• However, cancer did have a negative impact on people’s work abilities and/or their perceived work abilities for many people facing the disease. More than one third (36%) say that as a result of having cancer, they were unable to do their job as well as they could before, and one in five say having cancer had a negative impact on how they were viewed in terms of their ability to do their job (Chart 16).

• For minorities, cancer had significant impacts on their work situations. About in five say that the experience with cancer caused someone in their household to have a lower income (22%) or to lose/change jobs or work fewer hours (19%) (Chart 12). Among those who were employed when diagnosed, one in ten say as a result of having cancer they were removed from a job or changed jobs, and one in eight say they stayed in a job longer than they otherwise would to keep insurance coverage. Three percent say they were turned down for a job because of having cancer (Chart 16).

• Workers in lower-income families are more likely than their higher-income counterparts to report such problems (Chart 17).
SECTION 3: Problems with coordinating cancer care

Most people give good ratings to their own doctors, and to the health care system in general when it comes to treating cancer. However, significant minorities report problems with coordinating their cancer care. Such problems are more common among those who have suffered more severe cases of cancer, including those who have died, and those who were given worse prognoses at diagnosis.

- Most people give their own doctors excellent or good ratings, but significant minorities give their doctors only fair or poor ratings when it comes to their level of compassion (16%) and their level of expertise in dealing with medical issues (13%) (Chart 18).
  - Health professionals receive higher ratings from families when cancer is in remission or the person is still undergoing treatment, compared with those where someone has passed away from cancer (Chart 19). Older individuals and those with higher incomes also give their doctors higher ratings.
- Nearly three in ten (28%) say they do not have a doctor who pays attention to factors outside of their direct medical care, such as their support network for dealing with cancer (Chart 20).
  - Those with prostate or breast cancer are more likely than those with other types of cancer to say they have a doctor who pays attention to such factors (Chart 20).
- Significant minorities report problems with the coordination of their care for cancer, including receiving conflicting information from different health care providers (25%); being sent for duplicate tests (21%); and being confused about medication they were prescribed (20%). Half (50%) report experiencing at least one problem of this nature (Chart 21).
  - Those whose family member died of cancer or are currently undergoing treatment are more likely than those who have been cured of cancer to report these types of coordination problems (Chart 22). Also, those facing the most serious cases of cancer are more likely to report such problems (Chart 23). And among those who are now cancer-free, those who are limited in their activities report more problems than those who have been able to return to all their former pursuits (Chart 22).
- When asked to rate the American health care system when it comes to providing cancer care, more than four in ten people in families affected by cancer give the system a rating of “excellent” or “very good” (compared with 14% of the general public who give the same response to a similar question about the American health care system in general in a June 2005 survey). However, a significant share – 26% – rate the system as only “fair” or “poor” (Chart 24).
SECTION 4: The psychological impact of dealing with cancer and end-of-life care

Cancer places stress and strain on families in a variety of ways. However, not all these effects are negative; most people report that their experience with cancer had at least some positive impact on their life, and many say the experience changed their outlook on life in a positive direction. Family members report that the end-of-life experiences of those who died from cancer were generally as they wished them to be.

- Most people report facing cancer with a positive attitude – two-thirds say the person facing cancer was mostly optimistic about surviving when they first got their diagnosis, compared with one in five who say they were mostly pessimistic (Chart 25). Even among those who were told the cancer was likely to be fatal, six in ten (61%) say they were mostly optimistic. Those with lung cancer (41%) were the most likely to say they were pessimistic about surviving (Chart 26).
- Among those who are still living with cancer or have been cured, most families report that the experience with cancer has had at least some positive impact on the life of the person with cancer (63%) and on their own life (55% of family members). Smaller shares say the impact on the lives of the person with cancer (27%) and their own lives (34%) has only been negative (Chart 27). [Note: this question was not asked of those whose family members passed away.]
- More than half say the cancer experience has fundamentally changed their outlook on life, and the vast majority of these people say the change has been in a positive direction (forty-five percent overall say the experience changed their outlook for the better, compared with six percent who say it changed their outlook in a negative direction) (Chart 28). [Note: this question was not asked of those whose family members passed away.]
- The perception of positive impacts may happen over time – those who were diagnosed in the past year are less likely than others to say that cancer has had any positive impact on their lives, or that it changed their outlook for the better. And not surprisingly, those whose cancer is in remission or has been cured are more likely than those who still have cancer to report any positive impact on their life. Similarly, among those who are in remission or cured, those who have been able to return to all of their normal activities are more likely to report positive impacts than those with lingering disabilities due to cancer or their treatments (Chart 29).
- The “life-changing” aspect of cancer differs with age – those ages 65 and older are much less likely than younger people affected by the disease to say that the experience fundamentally changed their outlook on life (Chart 30).
SECTION 4: The psychological impact of dealing with cancer and end-of-life care (Continued)

- Most people (82%) who are cured or in remission from cancer think of themselves as cancer survivors (Chart 31). The people most likely to think of themselves as survivors are those who faced the most severe cases of cancer (Chart 31), and women who are recovered from breast cancer (Chart 32).

- Most family members of people who died from cancer give generally positive reports of their end-of-life experiences (Chart 33).
  - Nearly nine in ten (88%) people from families where someone had died of cancer report that their family member’s wishes about care at the end of life were generally followed.
  - About six in ten say that their family member’s passing was a “good death,” while just over a quarter considered it a “bad death.”
  - Almost six in ten (57%) report that their family who died of cancer had received hospice care, either at home or in a hospice facility.
SECTION 5: Reported cancer treatment experiences

*People report a variety of impacts of cancer treatment; nearly half say they experienced severe side effects of their treatment, and more than a third say the treatment left their appearance altered in a way that made it uncomfortable for them to go about their usual activities. In a hypothetical question, most people say they would prefer to be kept as comfortable and pain-free as possible if they were terminally ill, rather than having their life extended with more pain and discomfort; however, among people with cancer who had to make a decision about whether to undergo a treatment that would increase their chances of survival by only a small amount but potentially lead to very severe side effects, seven in ten say they chose to undergo the treatment.*

- Among those who have gone through cancer treatment (94%) (Chart 34), nearly half (47%) had very or somewhat severe side effects from the treatment, while the other did not have severe side effects (Chart 35).
  - Nearly half of those who had cancer treatment report having severe pain (45%), nausea (46%), and serious stress and anxiety (47%). Specifically among those who had chemotherapy (40%), two-thirds report hair falling out (Chart 36).
  - More than a third (36%) of those who had cancer treatment say that the treatment or surgery left their appearance altered in a way that made it uncomfortable to go out in public or go about their usual activities (Chart 35).
  - Among those who had chemotherapy, radiation treatment, or took prescription drugs related to their cancer treatment (73%), six in ten report that at some time the treatment left them so weakened or ill that they were unable to go to work or go about usual activities (Chart 35).
SECTION 5: Reported cancer treatment experiences (Continued)

• The standard statement among cancer specialists that people do not make the same choices in actual care that they do in a hypothetical questions seems to be borne out (Chart 37).
  
  • In a hypothetical question, about eight in ten (81%) say that if they were terminally ill, they would prefer being kept as comfortable and pain-free as possible, even if it means not living as long. Only twelve percent say they would want to have their life extended as long as possible, even if it means more pain and discomfort.
  
  • Yet among the 23% who had to make a very difficult decision about whether to undergo a treatment that would increase their chances of survival by only a small amount, but could potentially lead to severe side effects, about seven in ten (71%) say they chose to undergo treatment.
  
• Despite all of the media attention, few cancer patients report seeking alternative medicines and treatments.
  
  • Just over a quarter (27%) have taken alternative medicines or treatments, and most of those people report taking large doses of vitamins (17%) or dietary supplements other than conventional vitamins and minerals (16%). Far fewer report taking treatments they did not discuss with their doctor (4%), smoking marijuana for medicinal purposes (4%), or traveling to another country to get treatment not available in the U.S. (1%) (Chart 38).
Respondent Relationship to Person with Cancer

Percent of survey respondents saying the person in household with cancer was...

- Self: 46%
- Spouse: 25%
- Mother: 10%
- Father: 7%
- Grandparent: 4%
- Son or daughter: 3%
- Other family member living in household: 5%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Chart 2

Types of Cancers Reported

Percent saying the type of cancer they/their family member was diagnosed with was...

- Breast: 17%
- Prostate: 15%
- Melanoma: 11%
- Lung: 10%
- Colon or rectal: 10%
- Leukemia/Lymphoma: 8%
- Uterine/Cervical/Ovarian: 7%
- Other type of cancer: 20%

Note: Don’t know and refused responses not shown.

# Chart 3

## Time Since Cancer Diagnosis and Current Status

Percent who say they were/their family member was diagnosed with cancer...

<table>
<thead>
<tr>
<th>Time Since Diagnosis</th>
<th>In the past year</th>
<th>1-3 years ago</th>
<th>3-5 years ago</th>
<th>More than 5 years ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>20%</td>
<td>32%</td>
<td>27%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Note: Don’t know and refused responses not shown.


Percent who say their/their family member’s current status is...

<table>
<thead>
<tr>
<th>Current Status</th>
<th>In remission or cured</th>
<th>Still have cancer</th>
<th>Passed away</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>54%</td>
<td>23%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Note: Don’t know and refused responses not shown.
Chart 4

Reported Prognosis Given at Diagnosis

Percent who say when they were/their family member was diagnosed...

- Doctor said the cancer was likely to be fatal or lead to death: 16%
- Doctor told them likely outcome, but did not say cancer could go into remission or was likely to be fatal: 12%
- Doctor did not tell them what the likely outcome would be: 22%
- Don’t know/Refused: 9%
- Doctor said the cancer could be cured or go into long-term remission: 41%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
How much of a burden on your family are the costs of your/your family member’s overall medical care, including any services you need/your family member needs to cope with cancer?

29% Minor burden
52% Not a burden
17% Major burden
2% Don’t know/Refused

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Financial Burden of Cancer Care by Insurance Status, Income, and Age

Percent saying the cost of cancer care is a MAJOR burden on their family...

Insurance status since diagnosis
- Ever uninsured: 45%
- Always insured: 13%

Household income
- <$40K: 23%
- $40K+: 11%

Age of person with cancer
- 18-49: 28%
- 50-64: 21%
- 65+: 10%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Consequences of Financial Costs of Cancer

Percent who say each of the following happened to them/their family member as a result of the financial cost of dealing with cancer…

- Used up all or most of savings: 25%
- Borrowed money from relatives: 13%
- Contacted by a collection agency: 13%
- Unable to pay for basic necessities like food, heat, or housing: 11%
- Sought the aid of charity or public assistance: 11%
- Borrowed money/got a loan/another mortgage: 7%
- Declared bankruptcy: 3%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Chart 8

Consequences of Financial Costs of Cancer by Insurance Status

Percent who say each of the following happened to them/their family member as a result of the financial cost of dealing with cancer...

- Used up all or most of savings: 46% (Ever uninsured), 22% (Always insured)
- Borrowed money from relatives: 30% (Ever uninsured), 10% (Always insured)
- Contacted by a collection agency: 34% (Ever uninsured), 9% (Always insured)
- Unable to pay for basic necessities like food, heat, or housing: 41% (Ever uninsured), 7% (Always insured)
- Sought the aid of charity or public assistance: 35% (Ever uninsured), 7% (Always insured)
- Borrowed money/got a loan/another mortgage: 15% (Ever uninsured), 6% (Always insured)
- Declared bankruptcy: 6% (Ever uninsured), 3% (Always insured)

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reports of Cost-Based Treatment Decisions

Percent reporting that they/their family member did each of the following...

- Ever delayed or decided not to get care for cancer because of the cost
  - Total: 8%
  - Ever uninsured: 5%
  - Always insured: 3%

- Ever chose one cancer treatment over another because of the cost
  - Total: 4%
  - Ever uninsured: 13%
  - Always insured: 3%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reported Problems with Insurance Paying Cancer Bills

Among those with insurance, percent saying they/their family member had the following problems during cancer treatment...

- Plan paid less than expected for a medical bill: 23%
- Plan would not pay anything for care you received that you thought was covered: 13%
- Reached the limit of what insurance would pay for cancer treatment: 10%
- Were turned away or unable to get a specific treatment because of insurance issues: 8%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug 1-Sept 14, 2006)
Reported Problems Getting and Keeping Insurance Due to Cancer

Percent who said the following happened to them/their family member as a result of having cancer…

- Couldn’t buy health insurance because of having cancer: 11%
- Tried to purchase life insurance but were unable to do so: 8%
- Lost health insurance coverage: 6%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Family Impacts of Dealing With Cancer

Percent saying the experience with cancer had the following effects on their family...

- Caused someone in household to have emotional or psychological problems: 32%
- Caused severe strains with other family members: 25%
- Caused someone in household to have a lower income: 22%
- Caused someone in household to lose or change jobs or work fewer hours: 19%
- Caused someone in household (besides person with cancer) to have health problems: 10%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reports of Psychological Problems for Key Groups

Percent saying the experience with cancer caused someone in household emotional or psychological problems...

Current status of person with cancer

- Passed away from cancer: 59%
- Still have cancer: 31%
- In remission or cured: 23%

Age of person with cancer

- 18-49: 48%
- 50-64: 36%
- 65+: 23%

Among those who are in remission or cured: status since cancer recovery

- Limited in activities: 44%
- Return to normal: 15%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reports of Severe Family Strains for Key Groups

Percent saying the experience with cancer caused severe strains with other family members...

<table>
<thead>
<tr>
<th>Current status of person with cancer</th>
<th>Passed away from cancer</th>
<th>42%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Still have cancer</td>
<td></td>
<td>25%</td>
</tr>
<tr>
<td>In remission or cured</td>
<td></td>
<td>18%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of person with cancer</th>
<th>Passed away from cancer</th>
<th>41%</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-64</td>
<td></td>
<td>26%</td>
</tr>
<tr>
<td>65+</td>
<td></td>
<td>17%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Among those who are in remission or cured: status since cancer recovery</th>
<th>Limited in activities</th>
<th>31%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return to normal</td>
<td></td>
<td>14%</td>
</tr>
</tbody>
</table>

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Among those who were employed/family member was employed by someone else when diagnosed with cancer, percent who say the employer treated them...

- **Very well**: 76%
- **Somewhat well**: 10%
- **Not too well/Not well at all**: 7%
- **Don’t know/Refused**: 7%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug 1-Sept 14, 2006)
Reported Impacts of Cancer on Work

Among those who were employed/family member was employed when diagnosed with cancer, percent who say the following happened as a result of having cancer...

- Were unable to do job as well as before: 36%
- Had a negative impact on how you were viewed in terms of ability to do your job: 20%
- Stayed in a job longer than you otherwise would in order to maintain insurance: 12%
- Had to change jobs: 10%
- Removed from a job: 10%
- Turned down for a job*: 3%

Report any of the above problems: 44%

* Note: This question also includes those who were not employed when diagnosed.

Reported Impacts of Cancer on Work by Household Income

Among those who were employed/family member was employed when diagnosed with cancer, percent who say the following happened as a result of having cancer...

<table>
<thead>
<tr>
<th>Impact</th>
<th>Less than $40,000</th>
<th>$40,000 or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were unable to do job as well as before</td>
<td>48%</td>
<td>30%</td>
</tr>
<tr>
<td>Had a negative impact on how you were viewed in terms of ability to do your job</td>
<td>14%</td>
<td>33%</td>
</tr>
<tr>
<td>Stayed in a job longer than you otherwise would in order to maintain insurance</td>
<td>8%</td>
<td>19%</td>
</tr>
<tr>
<td>Had to change jobs</td>
<td>5%</td>
<td>21%</td>
</tr>
<tr>
<td>Removed from a job</td>
<td>5%</td>
<td>22%</td>
</tr>
<tr>
<td>Turned down for a job*</td>
<td>1%</td>
<td>6%</td>
</tr>
<tr>
<td>Report any of the above problems</td>
<td>36%</td>
<td>60%</td>
</tr>
</tbody>
</table>

* Note: This question also includes those who were not employed when diagnosed.

Percent who give the following ratings to doctors and health care professionals seen during the course of cancer treatment in terms of their...

- Excellent
- Good
- Fair
- Poor
- Don’t know/Refused

...Knowledge and expertise in handling medical issues

- 61% Excellent
- 24% Good
- 9% Fair
- 4% Poor
- 1% Don’t know/Refused

...Level of compassion

- 56% Excellent
- 24% Good
- 11% Fair
- 5% Poor
- 4% Don’t know/Refused

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Percent ratings the doctors and health care professionals seen during the course of their/their family member’s cancer treatment “excellent” or “good” in terms of their:

- **Knowledge and expertise in handling medical issues**
  - Passed away from cancer: 65%
  - Still have cancer: 83%
  - In remission or cured: 93%

- **Level of compassion**
  - Passed away from cancer: 64%
  - Still have cancer: 76%
  - In remission or cured: 90%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug 1-Sept 14, 2006)
Do you/Does your family member have a doctor who pays attention to factors outside of your/their direct medical care, including your/their support network for dealing with cancer?

<table>
<thead>
<tr>
<th></th>
<th>Have a doctor who pays attention</th>
<th>Do not have a doctor who pays attention</th>
<th>Don’t know/Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>63%</td>
<td>28%</td>
<td>9%</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>75%</td>
<td>18%</td>
<td>7%</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>72%</td>
<td>16%</td>
<td>12%</td>
</tr>
<tr>
<td>Other cancers</td>
<td>58%</td>
<td>32%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
<table>
<thead>
<tr>
<th>Problem</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received conflicting information from different doctors or health professionals</td>
<td>25%</td>
</tr>
<tr>
<td>Were sent for duplicate tests or diagnostic procedures by different health professionals</td>
<td>21%</td>
</tr>
<tr>
<td>Were confused about medication their doctor prescribed</td>
<td>20%</td>
</tr>
<tr>
<td>Left a doctor’s office without getting important questions about care or treatment answered</td>
<td>15%</td>
</tr>
<tr>
<td>Medical records or test results did not reach doctor’s office in time for appointment</td>
<td>13%</td>
</tr>
<tr>
<td>Report at least one of the above problems</td>
<td>50%</td>
</tr>
</tbody>
</table>

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug 1-Sept 14, 2006)
Reported Problems with Coordination of Care by Current Status of Person with Cancer

Percent who say the following ever happened during their/their family member’s cancer care…

<table>
<thead>
<tr>
<th>Current status of person with cancer</th>
<th>Among those in remission/cured: Status since recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passed away from cancer</td>
<td>Remission or cured</td>
</tr>
<tr>
<td>Still have cancer</td>
<td>Return to normal</td>
</tr>
<tr>
<td>Remission or cured</td>
<td>Limited in activities</td>
</tr>
<tr>
<td>Received conflicting information</td>
<td>43%</td>
</tr>
<tr>
<td>Sent for duplicate tests</td>
<td>29%</td>
</tr>
<tr>
<td>Confused about medication</td>
<td>41%</td>
</tr>
<tr>
<td>Left Dr’s office with questions unanswered</td>
<td>19%</td>
</tr>
<tr>
<td>Records didn’t reach office in time for appt.</td>
<td>13%</td>
</tr>
<tr>
<td>Any of the above</td>
<td>67%</td>
</tr>
</tbody>
</table>

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reported Problems with Coordination of Care by Prognosis Given at Diagnosis

Percent who say the following ever happened during their/their family member’s cancer care...

- Received conflicting information from different doctors or health professionals: 41% (19%)
- Were sent for duplicate tests or diagnostic procedures by different health professionals: 29% (20%)
- Were confused about medication their doctor prescribed: 35% (17%)
- Left a doctor’s office without getting important questions about care or treatment answered: 22% (11%)
- Medical records or test results did not reach doctor’s office in time for appointment: 17% (16%)

Report at least one of the above problems: 60% (48%)

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
How would you rate the health care system in America today when it comes to providing cancer care?

August 2006

- Excellent: 22%
- Very good: 21%
- Good: 26%
- Fair: 14%
- Poor: 12%

Comparison question asked of general public: How would you rate the health care system in America today?

June 2005

- Excellent: 11%
- Very good: 22%
- Good: 33%
- Fair: 30%
- Poor: 3%

Note: Don’t know and refused responses not shown.

Sources: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug. 1-Sept. 14, 2006)
Employee Benefit Research Institute *Health Confidence Survey* (conducted June 30-Aug. 6, 2005)
When you/your family member first found out you had cancer, were you/your family member mostly optimistic or mostly pessimistic about surviving cancer?

- Mostly optimistic: 67%
- Mostly pessimistic: 21%
- Don’t know/Refused: 12%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug 1-Sept 14, 2006)
Chart 26

Reported Attitude at Diagnosis by Type of Cancer

When you/your family member first found out you had cancer, were you/your family member mostly optimistic or mostly pessimistic about surviving cancer?

- **Prostate**: Mostly optimistic (74%), Mostly pessimistic (14%), Don’t know/Refused (11%)
- **Breast**: Mostly optimistic (70%), Mostly pessimistic (19%), Don’t know/Refused (11%)
- **Colon or rectal**: Mostly optimistic (64%), Mostly pessimistic (27%), Don’t know/Refused (9%)
- **Lung**: Mostly optimistic (49%), Mostly pessimistic (41%), Don’t know/Refused (10%)
- **Other cancers**: Mostly optimistic (69%), Mostly pessimistic (20%), Don’t know/Refused (11%)

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health *National Survey of Households Affected by Cancer* (conducted Aug 1-Sept 14, 2006)
Overall, would you say that this experience with cancer has had ANY positive impact on your/your family member’s life, or would you say the impact of this experience has ONLY been negative?*

- Any positive impact
- Only negative impact
- Don’t know/Refused

Reported impact on life of person with cancer

- 63%
- 27%
- 10%

For family members interviewed, reported impact on their OWN life

- 55%
- 34%
- 12%

* Note: This question was not asked of those whose family member had passed away.

Would you say that this experience with cancer has fundamentally changed your outlook on life, or not? (If changed: Would you say that change has been mostly in a positive direction, or mostly in a negative direction?)*

* Note: This question was not asked of those whose family member had passed away.

Overall Impact of Cancer by Key Groups

Percent saying the experience with cancer had ANY positive impact on the life of the person with cancer…*

Current status of person with cancer

<table>
<thead>
<tr>
<th>Status</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Still have cancer</td>
<td>52%</td>
</tr>
<tr>
<td>In remission or cured</td>
<td>68%</td>
</tr>
</tbody>
</table>

Among those who are in remission or cured: status since cancer recovery

<table>
<thead>
<tr>
<th>Status</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited in activities</td>
<td>62%</td>
</tr>
<tr>
<td>Return to normal</td>
<td>71%</td>
</tr>
</tbody>
</table>

Time since cancer diagnosis

<table>
<thead>
<tr>
<th>Time Since Diagnosis</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 year</td>
<td>54%</td>
</tr>
<tr>
<td>1-3 years</td>
<td>67%</td>
</tr>
<tr>
<td>More than 3 years</td>
<td>65%</td>
</tr>
</tbody>
</table>

* Note: This question was not asked of those whose family member had passed away.

Reported Change in Outlook Due to Cancer by Age of Respondent

Would you say that this experience with cancer has fundamentally changed your outlook on life, or not?*

- Yes, fundamentally changed outlook
- No, did not fundamentally change outlook

<table>
<thead>
<tr>
<th>Age</th>
<th>Yes (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-49 years</td>
<td>69%</td>
<td>31%</td>
</tr>
<tr>
<td>50-64 years</td>
<td>59%</td>
<td>41%</td>
</tr>
<tr>
<td>65+ years</td>
<td>36%</td>
<td>64%</td>
</tr>
</tbody>
</table>

* Note: This question was not asked of those whose family member had passed away.

Among those whose cancer is cured or in remission: Do you think of yourself/Does your family member think of himself/herself as a cancer survivor, or not?

<table>
<thead>
<tr>
<th></th>
<th>Yes, think of self as survivor</th>
<th>No, do not think of self as survivor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>82%</td>
<td>16%</td>
</tr>
<tr>
<td>Those who were told their cancer could go into remission</td>
<td>77%</td>
<td>21%</td>
</tr>
<tr>
<td>Those who were not told their cancer could go into remission</td>
<td>87%</td>
<td>12%</td>
</tr>
</tbody>
</table>

Note: Don’t know and refused responses not shown.

Who Thinks of Themselves as “Survivors”?

Among those whose cancer is cured or in remission: Do you think of yourself/Does your family member think of himself/herself as a cancer survivor, or not?

- Yes, think of self as survivor
- No, do not think of self as survivor

**Breast**
- 94%
- 6%

**Prostate**
- 85%
- 13%

**Other cancers**
- 77%
- 21%

Note: Don’t know and refused responses not shown.

Chart 33

End-of-Life Care Among Those Who Passed Away

Among those whose family member passed away:

In your opinion, were your family member’s wishes about care at the end of his/her life generally followed, or not?

- Yes: 88%
- No: 4%
- Don’t know/Refused: 8%

The death of a loved one is a traumatic experience, but some people have used the term “good death” to refer to one that goes about as well as a person could expect. Was your family member’s death a “good death,” or did things happen that made it a “bad death”?

- “Good death”: 62%
- “Bad death”: 27%
- Don’t know/Refused: 11%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reported Treatments for Cancer

Percent who say they/their family member had the following treatments for cancer...

- Surgery, such as the removal of a tumor or other cancerous mass: 67%
- Prescription drugs related to cancer treatment: 59%
- Radiation treatment: 42%
- Chemotherapy: 40%
- Any of the above: 94%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
Reported Severity of Cancer Treatment Effects

Among the 94% who say they/their family member had chemotherapy, radiation, surgery, or prescription drugs related to their cancer treatment, percent who report...

- Side effects of treatment were very or somewhat severe: 47%
- Treatment ever left them so weakened or ill that they were unable to go to work or go about usual activities*: 60%
- Treatment or surgery left their appearance altered in a way that made it very uncomfortable to go out in public or go about usual activities: 36%

* Asked only of those who had chemotherapy, radiation, or prescription drugs.

Among the 94% who say they/their family member had chemotherapy, radiation, surgery, or prescription drugs related to their cancer treatment, percent who report the following side effects…

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hair falling out*</td>
<td>67%</td>
</tr>
<tr>
<td>Serious stress and anxiety</td>
<td>47%</td>
</tr>
<tr>
<td>Nausea</td>
<td>46%</td>
</tr>
<tr>
<td>Severe pain</td>
<td>45%</td>
</tr>
<tr>
<td>Report any of the above side effects</td>
<td>72%</td>
</tr>
</tbody>
</table>

* Among those who had chemotherapy.

Chart 37

Hypothetical Preference vs. Actual Choice of Care

Percent who say that if they were terminally ill, they would prefer...

- Having your life extended as long as possible, even if it means more pain and discomfort
- Being kept as comfortable and pain-free as possible, even if it means not living as long

12% 81%

Among those who say they/their family member ever had to make a decision about whether to undergo a treatment that would increase their chances of survival by only a small amount, but could potentially lead to severe side effects, percent who say they chose to...

- Undergo the treatment
- Not undergo the treatment

71% 28%

Note: Don’t know and refused responses not shown.

Reported Use of Alternative Treatments

Percent who say they/their family member did the following to try to deal with their cancer…

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Took large doses of vitamins</td>
<td>17%</td>
</tr>
<tr>
<td>Took dietary supplements other than conventional vitamins and minerals</td>
<td>16%</td>
</tr>
<tr>
<td>Took treatments you did not discuss with your doctor</td>
<td>4%</td>
</tr>
<tr>
<td>Smoked marijuana for medical purposes</td>
<td>4%</td>
</tr>
<tr>
<td>Traveled to another country to get treatment not available in the U.S.</td>
<td>1%</td>
</tr>
</tbody>
</table>

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health National Survey of Households Affected by Cancer (conducted Aug 1-Sept 14, 2006)
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