Nationwide Survey of Patients’ Perspectives Regarding Their Radiation and Multidisciplinary Cancer Treatment Experiences

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QUESTION ASKED: How do patients who receive radiation therapy (RT), with or without surgery and systemic therapy, perceive their treatment toxicities and their level of informed decision making?

SUMMARY ANSWER: In this nationwide survey of 403 patients, the majority found their RT toxicity experience to be no worse than expected. However, across radiation, surgery, and chemotherapy, approximately one in three patients experienced treatment toxicities they wished they had known more about.

WHAT WE DID: We conducted a Web-based survey of patients with cancer across all regions of the United States treated with RT within the past 5 years.

WHAT WE FOUND: Among all respondents, 82% reported having enough information on what adverse effects to expect before RT. However, 37% experienced radiation adverse effects that they wished they had known more about, and similar proportions of patients treated with chemotherapy (36%) and surgery (34%) experienced toxicities related to those treatments that they wished they had known more about.

BIAS, CONFOUNDING FACTORS: As in any survey study, bias is possible as a result of factors such as selective nonresponse or inaccurate recall.

REAL-LIFE IMPLICATIONS: Patient experiences with RT toxicities are mostly congruent with expectations. Efforts to improve physician-patient communication and informed consent processes across cancer modalities are merited to reduce the number of inadequately informed patients.

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abstract

PURPOSE The perspectives of patients with cancer about their treatment can inform interventions to improve the approaches of treating oncologists and experiences of future patients. We sought to identify areas where current toxicity management, informed consent processes, and physician-patient communication merit improvement.

METHODS In a Web-based survey administered from March to May 2018 using quota-based sampling to draw a nationwide sample of US patients with cancer treated with radiotherapy within the past 5 years, we evaluated patient perceptions of adequacy of information about adverse effects, severity of actual adverse effects experienced, and experiences divergent from expectations.

RESULTS Among 403 respondents, 18% felt inadequately informed about what adverse effects to expect from radiotherapy, and 37% experienced radiation adverse effects that they wished they had known more about. Similar proportions of patients treated with chemotherapy (36%) and surgery (34%) experienced toxicities related to those treatments that they wished they had known more about. Patients who noted their adverse effects to be minimal versus severe were significantly more likely to feel informed about radiotherapy adverse effects (odds ratio, 13.05; 95% CI, 5.6 to 30.38; P < .001). Across all evaluated measures, a majority of patients indicated that they did not experience the potentially anticipated radiotherapy adverse effect or that it was the same as or better than expected.

CONCLUSION This study suggests that experiences with radiation adverse effects generally are congruent with expectations. Nevertheless, improvement of pretreatment counseling across all cancer therapy modalities seems warranted to improve informed decision making and treatment experiences.

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INTRODUCTION

Fear of cancer therapy can influence patients’ treatment decisions.1-4 The perspectives of patients who have received cancer treatment can provide valuable insights to inform other patients’ decisions about whether to receive treatment and to help them to understand what to expect. This is particularly relevant to patients who are considering radiation therapy in the context of multimodality cancer care because data indicate that despite initial feelings of fear and anxiety, most patients have little or no baseline knowledge about radiation therapy.1,5 Analysis of patients’ ratings of the severity of their own adverse effects and how patients perceive their actual adverse effects to have diverged from expectations can identify areas where current toxicity management, informed consent processes, and physician-patient communication might need improvement. Furthermore, the identification of subsets of patients who believe that they were inadequately informed about treatment-related adverse effects and exploration of their characteristics are important steps to help to design and implement communication interventions. Therefore, we sought to ascertain the experiences of a large, nationwide sample of patients who received radiation therapy alone or as part of multimodality cancer management. By drawing on the perspectives of more than 400 patients with cancer, we examined how informed decision making intersects with patients’ expectations and experiences with regard to treatment-related toxicities.

METHODS

Sampling and Survey Administration
A nationwide survey of patients with cancer treated with radiation therapy was conducted by Public
Opinion Strategies (Alexandria, VA). The sample of patients was provided by Dynata (formerly Research Now, Plano, TX), which uses invitations, including e-mail, phone alerts, banners, and messaging, on community Web sites to enroll people in research panels. Dynata then screens and recruits participants with quotas for sex, region, age, ethnicity, and education to achieve a sample with demographics representative of the US census. Dynata uses an incentive scale that is based on set time increments, and the incentive options allow panelists to redeem from a large range of gift cards, charitable contributions, and other products or services after completing the survey.

Survey invitations were sent to respondents on the Dynata panel who had previously indicated that they had been diagnosed with or treated for cancer. The panel company collects and regularly updates information about its respondents through screener surveys and member profiles. Quotas were set for sex, region, age, ethnicity, and education. Modest weighting also was applied to these same variables upon completion of interviewing on the basis of demographic information available from the National Cancer Database, American Cancer Society, American Society for Radiation Oncology, and other sources.

The survey was administered online from March 5 to 15, 2018, and on May 8, 2018. Invitations were sent to 13,069 adults, of whom 78% (n = 10,171) started to take the survey. Of these, 4% (n = 403) completed the survey, 93% (n = 9,494) were ineligible, and 3% (n = 274) were eligible but did not complete the survey. Top reasons for ineligibility included individuals who were over the quota set for US region (51%) or age (14%), did not receive radiation therapy (20%), did not have cancer (8%), did not start treatment (3%), or received treatment more than 5 years ago (3%).

**Questionnaire Design and Measures**

The questionnaire was designed with the goal of assessing the level of informed treatment decision making and how patients perceived their radiation adverse effects compared with what they expected. The questionnaire was developed through literature review and input from content experts and Public Opinion Strategies and evaluated toxicity measures adapted from validated patient-reported questionnaires.1,6,7

To evaluate the adequacy of information about treatment-related toxicity, using binary (yes/no) response options, patients were asked whether they had enough information on what adverse effects to expect from treatment (with patients asked separately about adverse effects from radiation therapy, chemotherapy, and surgery) and whether they experienced adverse effects about which they wished they had known more about, and these comments were thematically categorized by an expert physician-reviewer. Patients also were asked to identify their top concerns and adverse effects at baseline. To evaluate divergence of expectations from experience, patients were asked whether their actual experience with each specific adverse effect from a list was as expected, worse than expected, or better than expected or whether they did not experience the specific adverse effect. To evaluate patient perceptions of actual toxicity severity, they were asked to rate the severity of their overall adverse effect experience using a scale from 0 (no adverse effects) to 100 (most-severe adverse effects), which was analyzed as a continuous variable and broken into categories defined a priori as minimal (0 to 25), modest (26 to 74), and severe (75 to 100).

Questions also measured respondent demographics, cancer treatment history, and sources of information. Specifically, we evaluated age, sex, education, cancer site, ethnicity, US region, sources of information about cancer treatment (cancer support group, primary care provider, television, radio, newspaper, magazine, book, medical/cancer-related Web site, friends and family, personal experience, other patients with cancer), and receipt of chemotherapy. The survey questionnaire is included in the Data Supplement.

**Statistical Analysis**

To account for differential nonresponse, complex survey weights were applied before analysis.8 We report unweighted number values and weighted percentages throughout. Patient responses were evaluated across all cancer types and in subgroups of breast, prostate, and all other remaining cancers. Patients could select having multiple types of cancer for the initial response. For analyses with groups specifically on the basis of disease site, the breast cancer and prostate cancer subgroups excluded patients with multiple cancers; all patients with more than one type of cancer were categorized as other. Responses were compared using $\chi^2$ or Fisher’s exact test. Factors associated with feeling informed about adverse effects among patients treated with radiation therapy were evaluated using univariable analyses and multivariable regression models. Covariates included prespecified demographic, clinical, and treatment factors as follows: age, sex, education, receipt of chemotherapy and surgery, cancer site, geographic region, sources of information, time of survey completion since treatment, and patient-reported adverse effect severity rating. Hosmer-Lemeshow goodness-of-fit analysis was included for the regression model. $P < .05$ was considered statistically significant.

**RESULTS**

**Patient Characteristics**

In total, 403 patients with cancer who had undergone radiation therapy in the past 5 years were evaluated. Breast
(40%) and prostate (21%) were the most common cancers represented; for analyses specific to cancer type, patients were categorized as having received radiation therapy specifically for breast cancer only (37%), prostate cancer only (19%), or another type of cancer (44%). Approximately 70% were age 55 years or older, and 63% were female. Participants represented all US regions. Among all patients, 68% received radiation therapy within the past 2 years; 41% also received chemotherapy, and 52% underwent surgery for the management of their cancer (see the Data Supplement for additional details of the characteristics of the survey sample).

Information Sources and Perceived Importance
Fifty-five percent of patients reported talking with their primary care physicians about cancer treatment options, and nine in 10 of these patients noted the advice of their primary care physicians to be very important (64%) or somewhat important (29%) in their decision making. Common sources of information used in treatment decision making included medical or cancer-related Web sites (50%), family and friends (33%), prior patient experiences (29%), and cancer support groups (20%). A subset of patients (26%) reported only receiving information about cancer treatment options from their physicians, and this was a larger group than those who received information from one, two, or three additional sources (24%, 20%, and 19%, respectively).

Most patients (68%) perceived their radiation oncologist to have the same or more cancer knowledge as other oncologists on their treatment team. This view was more common among patients with breast cancer (70%) and other cancers (72%) than among those with prostate cancer (54%; \( P < .001 \); Data Supplement).

Adequacy of Information
Among all respondents, 82% reported having enough information on what adverse effects to expect before radiation therapy. Similarly, in the subgroup of patients also treated with chemotherapy and/or surgery, 74% and 80%, respectively, felt they had enough information about potential adverse effects from the treatments (Table 1). However, 37% of all patients experienced radiation adverse effects about which they wished they had known more before treatment (Table 1). Similarly, 36% and 34% of patients treated with chemotherapy and/or surgery, respectively, experienced adverse effects that they wished they had known more about (Table 1). Of submitted comments that detailed treatment-related adverse effects that respondents wished in retrospect to have known more about, top themes for radiation adverse effects included skin toxicity, GI symptoms, and fatigue. The chemotherapy adverse effects identified most frequently were nerve damage, GI symptoms, and fatigue. The most common surgical adverse effects patients wished they had known more about were pain and nerve damage/numbness.

Perceived Severity of Toxicity
When rating their actual radiation adverse effect experience using a scale from 0 (minimal) to 100 (severe), the mean rating of severity among all patients was 45 (standard deviation, 32), with 39% reporting their adverse effects to be minimal (0 to 25), and 29% reporting their adverse effects to be severe (75 to 100). The mean radiation adverse effect rating score was significantly higher in patients treated with trimodality therapy versus radiation therapy alone (51 vs 37; \( P = .01 \)). In comparison, in the subgroups of patients who also received chemotherapy or surgery, the mean ratings were 63 for chemotherapy and 47 for surgical adverse effects.

Toxicity Expectations and Divergence From Experiences
The most frequent adverse effect concerns that patients had before undergoing radiation included feeling tired (56%), feeling weak (50%), and skin burning (46%). Other practical concerns were expressed by a substantial minority, including not being able to carry out normal daily functions/work (37%), the cost of treatment (17%), and travel distance (15%; Fig 1). Across all evaluated measures, the majority of patients indicated that they did not experience a self-anticipated adverse effect or that it was the same or not as bad as expected; however, a sizable minority noted specific toxicities to be worse than expected (Fig 2). Most prominently, 29% and 31% of patients noted feeling tired or changes to their energy level, respectively, that were worse than expected. Fatigue was particularly pronounced in patients with breast cancer, with 35% reporting feeling more tired than expected (Fig 2). Modality also influenced divergence from expectations, with toxicities including fatigue (\( P < .001 \)), weakness (\( P < .002 \)), and pain (\( P < .001 \)) found to be worse than expected in significantly fewer patients treated with radiation alone versus trimodality therapy that included surgery and systemic therapy (Fig 2).

Correlates of Adequate Information
No significant associations were found between whether patients felt adequately informed about adverse effects of radiation therapy and characteristics, including age, sex, education level, ethnicity, cancer site, or US region (Data Supplement). On multivariable analysis, patients who noted their adverse effects to be minimal (0 to 25) versus severe (75 to 100) were more likely to feel informed about radiation adverse effects (odds ratio, 13.05; 95% CI, 5.6 to 30.38; \( P < .001 \)). Those who obtained information from family, neighbors, and friends were less likely to feel informed about radiation adverse effects (odds ratio, 0.49; 95% CI, 0.28 to 0.87; \( P = .015 \); Table 2).

DISCUSSION
This contemporary study of a nationwide sample of patients with cancer who have received multidisciplinary care provides unique insights. It illuminates the level of informed
TABLE 1. Patient Responses to Feeling Informed About Adverse Effects From Cancer Treatment

<table>
<thead>
<tr>
<th>Question</th>
<th>Total, No.</th>
<th>Yes, No.</th>
<th>%*</th>
<th>No.</th>
<th>%*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel you had enough information on what adverse effects you could expect?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation therapy adverse effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All patients</td>
<td>403</td>
<td>331</td>
<td>82.3</td>
<td>72</td>
<td>17.7</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>151</td>
<td>122</td>
<td>81.2</td>
<td>29</td>
<td>18.8</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>74</td>
<td>65</td>
<td>87.8</td>
<td>9</td>
<td>12.2</td>
</tr>
<tr>
<td>Other cancer</td>
<td>178</td>
<td>144</td>
<td>81.0</td>
<td>34</td>
<td>19.0</td>
</tr>
<tr>
<td>Chemotherapy adverse effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All patients</td>
<td>166</td>
<td>124</td>
<td>74.7</td>
<td>42</td>
<td>25.3</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>64</td>
<td>51</td>
<td>80.3</td>
<td>13</td>
<td>19.7</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>6</td>
<td>5</td>
<td>83.0</td>
<td>1</td>
<td>17.0</td>
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<tr>
<td>Other cancer</td>
<td>96</td>
<td>68</td>
<td>70.5</td>
<td>28</td>
<td>29.5</td>
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<tr>
<td>Surgery adverse effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All patients</td>
<td>214</td>
<td>171</td>
<td>80.0</td>
<td>43</td>
<td>20.0</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>116</td>
<td>93</td>
<td>80.3</td>
<td>23</td>
<td>19.7</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>17</td>
<td>14</td>
<td>82.8</td>
<td>3</td>
<td>17.2</td>
</tr>
<tr>
<td>Other cancer</td>
<td>81</td>
<td>64</td>
<td>78.8</td>
<td>17</td>
<td>21.2</td>
</tr>
</tbody>
</table>

Were there adverse effects you experienced that you wish you had known more about?

| Radiation therapy adverse effects             |            |          |     |     |     |
| All patients                                  | 403        | 149      | 37.2| 254 | 62.8|
| Breast cancer                                 | 151        | 48       | 31.5| 103 | 68.5|
| Prostate cancer                               | 74         | 22       | 29.7| 52  | 70.3|
| Other cancer                                  | 178        | 79       | 45.1| 99  | 54.9|
| Chemotherapy adverse effects                  |            |          |     |     |     |
| All patients                                  | 166        | 71       | 43.6| 95  | 56.4|
| Breast cancer                                 | 64         | 23       | 35.4| 41  | 64.6|
| Prostate cancer                               | 6          | 1        | 17.0| 5   | 83.0|
| Other cancer                                  | 96         | 35       | 36.9| 61  | 63.1|
| Surgery adverse effects                       |            |          |     |     |     |
| All patients                                  | 214        | 73       | 33.8| 141 | 66.2|
| Breast cancer                                 | 116        | 41       | 34.9| 75  | 65.1|
| Prostate cancer                               | 17         | 6        | 35.7| 11  | 64.3|
| Other cancer                                  | 81         | 26       | 31.8| 55  | 68.2|

*All percentages are weighted percentages.

decision making and information sources of patients with cancer. Specifically, it affords key information about the nature and severity of the adverse effects patients perceived to be related to their treatments, how actual toxicity experiences diverged from expectations, and how factors correlated with inadequate information about adverse effects. The data indicate that patients’ experiences with radiation adverse effects are mostly in line with expectations because most patients either did not experience adverse effects or found them to be as expected or better than expected. These data also affirm the important role perceived by patients of the radiation oncologist in multidisciplinary cancer care. These patient-reported data are congruent with multiple studies that have reported increased treatment-related toxicities with multimodality cancer therapy.9-12 Our findings with regard to radiation-related toxicities also are generally consistent with previous studies that evaluated the toxicity experiences of large population-based samples of patients treated with radiation.13,14 However, prior studies have not, to our knowledge, provided a comprehensive analysis of patients’ perceptions with regard to adequacy of information about adverse effects as provided in this study.

Although the majority of patients in the current study reported feeling adequately informed with regard to adverse effects across their cancer therapies, a meaningful minority experienced unexpected adverse effects. Across all modalities of cancer therapy, including surgery, radiation therapy, and chemotherapy, approximately one in five patients reported insufficient information on adverse effects, and one in three experienced adverse effects they wish that they had known more about. This finding was consistent across sex, education level, age, ethnicity, US region, and cancer type. Indeed, prior studies have documented that patients with cancer strongly want to know about all possible adverse effects of treatment15 and have found that a notable proportion of patients report having received insufficient information from their health care providers.16 Data also suggest that how actual adverse effects compare with expectations may be of greater impact to patients than the absolute severity of adverse effects.17 Our finding of nearly one in three patients who experienced unexpected toxicities regardless of treatment modality should be a call to action to improve and increase access to resources that can reduce the number of patients who feel inadequately informed about treatment toxicities.

Specific to radiation therapy, the greatest divergence between pretreatment expectations and the actual toxicity experience were related to changes in patients’ energy levels, particularly in patients treated with multimodality therapy. We may see a signal of the implication of this toxicity reflected in the significant minority of patients who reported worse-than-expected limitations in daily activities/work, social/recreational activities, and family life. In addition, our findings suggest that counseling on both potential adverse effects and their range of severity is essential to the informed consent process. Although higher-grade toxicities are rare (eg, prospective data have shown rates of high-grade fatigue from adjuvant breast radiation therapy to be 19%18 and rates of high-grade bowel toxicity from salvage prostate radiation to be 13%19), they do, in fact, occur. Our finding that patients who experienced severe...
radiation adverse effects are more likely to feel inadequately informed supports efforts to improve how we counsel patients on the potential range of toxicity severities.

This study shares the experiences of more than 400 patients with cancer and offers a needed real-world assessment on the adequacy of current patient-physician communication and informed consent processes. Limitations inherent to survey-based research apply to this study, specifically as it pertains to the response rate and responder bias. Specifically, our sample included few patients with less than a high school education, which limited our ability to appreciate fully the experiences of these patients. In addition, the Web-based interface of the survey and the recruitment methods of Dynata may have introduced additional selection bias to our findings. Furthermore, this cross-sectional survey was used at a single point of time; therefore, recall bias may have affected the findings. However, the concordance of our data with previously published patient-reported outcomes and the diverse sample of participating patients strengthen the validity of our findings.

In conclusion, the evaluation of the experiences of patients who receive cancer treatment provides actionable insights to improve the decisions and experiences of the hundreds of thousands of patients diagnosed with cancer who consider treatment options each year. In the radiation oncology domain, the fact that more than two thirds of patients perceive their radiation oncologist to have the same or more cancer knowledge as their other oncologists provides valuable information. This feedback indicates that the voice of the radiation oncologist is important to patients with cancer and that patients value a well-balanced description of the benefits and potential toxicities associated with radiation as they navigate the cancer treatment process. In addition, with the majority of patients indicating that they get information on cancer treatments from their primary care providers and Web sites, it is essential to target these sources and ensure that they are up to date,
especially because studies have indicated the need for increasing awareness of radiation therapy and oncology in basic medical training.20-22 Oncology professional societies and patient advocacy groups have an opportunity to leverage this information and the expertise of experienced professionals to develop and disseminate resources to
augment physician-patient communication and consent processes. With optimal information, patients are better equipped to make informed decisions and engage treatment with confidence as well as to have realistic expectations about the anticipated benefits and toxicities they are most likely to experience.

REFERENCES


AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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