Scientific Article

Reddit and Radiation Therapy: A Descriptive Analysis of Posts and Comments Over 7 Years by Patients and Health Care Professionals

Joel Thomas BA a, Arpan V. Prabhu MD b,c,*, Dwight E. Heron MD, MBA, FACRO FACR c, Sushil Beriwal MD, MBA c,*

aUniversity of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania; bDepartment of Radiation Oncology, UAMS Winthrop P. Rockefeller Cancer Institute, Little Rock, Arkansas; and cDepartment of Radiation Oncology, University of Pittsburgh School of Medicine and UPMC Hillman Cancer Institute, Pittsburgh, Pennsylvania

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Abstract

Purpose: Reddit is a social media platform that allows health care professionals (HPs) to anonymously interact with patients. We analyzed content about radiation therapy (RT) on Reddit.

Methods and Materials: Reddit.com/r/cancer was queried with 20 search terms related to RT: IMRT, 3D-CRT, SBRT, EBRT, XRT, radiation, radiotherapy, RT, radio, rad, rads, gamma, gamma knife, gammatrak, cyberknife, cyberknife, cyber, brachytherapy, brachy, and cobalt. The search aimed to identify all posts discussing RT. A random sample of posts and their top 3 comments was selected to generate qualitative thematic codes per author consensus, which were used to characterize all posts and their top 3 voted comments. Posts were analyzed for time to first reply, mention of any specific RT modality, whether a self-identified HP responded, and time to first highly voted comment by an HP.

Results: Exactly 190 posts about RT by 178 users were shared from February 2011 to May 2018, and 468 replies by 295 users were also analyzed. Twenty-nine of these users (9.8%) were HPs; however, 48 of 181 top comments were contributed by HPs compared with 45 of 288 non-top comments by HPs (odds ratio, 1.95; 95% confidence interval [CI], 1.23-3.08; \( P < .004 \)). The most common themes were treatment questions, chronology, and information; toxicities; and social support. The median time to first comment after posting was 64.0 minutes (95% CI, 53.0-82.0), and median time to first highly voted comment from an HP was 264.0 minutes (95% CI, 153.5-427.9; \( U = 4123.5; P < .0001 \) 2-tailed). Fifty-three posts (27.9%) identified a specific RT modality, with proton therapy (7.4%), CyberKnife (5.3%), brachytherapy (4.2%), and whole brain radiation (4.2%) being the most common.

Conclusions: HPs did not reply often to RT posts and generally took longer to do so, but their replies were valued by users. Common themes included treatment questions, chronology, and treatment; toxicities; and social support. Proton therapy received notable attention.

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* Co-corresponding authors. Department of Radiation Oncology, UAMS Winthrop P. Rockefeller Cancer Institute, Little Rock, AR (Prabhu); Department of Radiation Oncology, University of Pittsburgh School of Medicine and UPMC Hillman Cancer Institute, Pittsburgh, PA (Prabhu and Beriwal).

E-mail addresses: ArpanPrabhuMD@pitt.edu (A.V. Prabhu), beriwal@upmc.edu (S. Beriwal).

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Introduction

Social media has attracted attention in public health research because it can reveal attitudes and practices that are underrepresented in traditional surveys. Moreover, online platforms allow health care professionals (HPs) to directly interact with patients, often in an anonymous context to minimize fears about potentially compromising professional identity.

Reddit.com is a discussion website that encourages conversation about a wide variety of topics on various subreddits. Users can create anonymous profiles and engage in individual subreddits (eg, reddit.com/r/cancer and reddit.com/r/food) by starting written threads and posting pictures and videos with discussion in comments. Different users and subreddits afford a variety of means of engagement. Individuals on reddit.com/r/cancer, for example, may ask questions to self-identified HPs about what to expect with treatment. Reddit is among the most popular social media websites, ranking fifth for internet traffic in the United States, surpassing Twitter, Instagram, and Tumblr.

Multiple simultaneous conversations may take place at once in a given comments section for a post via comment trees, which allow users to comment both on the post itself and comments within the post. Therefore, a given post may have several independent conversations occurring simultaneously, represented as comment trees in response to a single original comment. New comment trees are distinguished from responses to an existing comment tree by the degree of indentation in the comment formatting. Subreddits may have users who actively post, subscribers who post or simply choose to browse content, and moderators who regulate the subreddits (eg, deleting threads that violate the individual subreddit’s rules). Posts are archived and easily accessible, allowing researchers easy access to a substantial corpus of data. Prior studies have analyzed posts to identify patient sentiment about mental illness, dermatologic disease, and gout.

The cancer subreddit (reddit.com/r/cancer) is highly active with >21,000 subscribers. Its members include patients and their family members, as well as HPs and scientists. However, no studies have examined Reddit discussions about radiation therapy (RT). Given the recent American Society of Radiation Oncology (ASTRO) initiative for greater radiation oncology representation in social media, the field may benefit from understanding and engaging through this medium about RT’s contribution to cancer care.

Herein, we present an analysis of Reddit discussion about RT by patients and HPs. We aimed to characterize discussions on the cancer subreddit about RT and to identify interactions between patients and their families with HPs.

Methods and Materials

Data collection

Posts about radiation therapy and comments

Because this analysis exclusively involved public online material, institutional board approval was unnecessary. A single author (J.T.) manually collected all English-language posts about RT in the cancer subreddit (reddit.com/r/cancer) using Reddit’s public search feature. Exactly 20 search terms were queried: IMRT, 3D-CRT, SBRT, EBRT, XRT, radiation, radiotherapy, RT, radio, rad, rads, gamma, gammaxx, gammaxknife, cyberknife, cyber, brachytherapy, brachy, and cobalt. These terms were believed to be exhaustive because search results for each term contained posts with conjunctions of the queried term. For example, searching “radiation” also revealed posts that contained the term “radiation treatment.” All collected posts were subsequently independently reviewed by a second author (A.V.P.) for final inclusion in the database. Posts that did not appear to discuss RT were excluded.

The following information was collected for each post: time and date submitted, number of comments, username of poster, whether a specific RT modality was mentioned (eg, SBRT), and whether a self-identified HP commented on the post. The first comment for each post was also analyzed by sorting the post comments by “old” and identifying the first comment. For each post, the time of the first comment and username of the author of the first comment were also collected. Deleted posts and comments were obtained using the removeddit application (https://github.com/JubbeArt/removeddit). Pushshift Reddit API was used to collect the total number of posts submitted to reddit.com/r/cancer.

The top 3 independent comments for each post were also collected. We chose to collect original independent comments to best capture the breadth of perspectives offered in response to individual posts. Thus, the top independent comments for each post were identified by
sorting the comments by “top” and selecting the first 3 comments without any indentation to the right. For posts without at least 3 independent comments, we collected as many independent comments as possible using the same approach. For all top comments, we collected the date and time of the comment, as well as the username of the author who wrote the comment. We further assessed whether a self-identified HP authored the comment.

**Post and comment coding**

We generated a random sample of 20 posts and their top comments using Google’s random number generator. Two authors (J.T. and A.V.P.) performed manual coding of these posts and comments to generate a preliminary list of 29 codes. Broad categories for codes included thematic content (eg, humor, comparison with chemotherapy, family members), organ system involved (eg, lung, breast), and treatment modality (eg, SBRT). The rest of the posts and comments in the database were subsequently coded using this preliminary list, with additional codes generated at the authors’ discretion if thematic content could not be captured with the original list. An initial review of the posts and comments yielded 39 codes, which were subsequently condensed to 34 broader themes.

Upon completion of coding posts and comments in [reddit.com/r/cancer](https://www.reddit.com/r/cancer), we queried our 21 search terms in other smaller cancer subreddits: r/radiationtherapy (180 subscribers), r/radiationoncology (192 subscribers), r/ovariancancer (138 subscribers), r/testicularcancer (647 subscribers), r/multiplemyeloma (414 subscribers), r/prostatecancer (517 subscribers), r/ckcancer (1500 subscribers), r/cancersurvivors (237 subscribers), r/lungcancer (202 subscribers), r/melanoma (443 subscribers), r/braincancer (1000 subscribers), r/leukemia (478 subscribers), r/lymphoma (624 subscribers), and r/pancreaticcancer (757 subscribers). However, we chose not to proceed with an exhaustive analysis of these communities because they contained orders of magnitude fewer subscribers than r/cancer (20,600 subscribers), did not have as strong an HP presence, and appeared to have similar content upon review by authors.

**Statistical analysis**

The odds ratio for top comment versus non–top comment by HP versus non-HP was calculated. The Mann-Whitney U test was used to assess differences in time to first comment by anyone versus time to first high-quality comment by an HP. SPSS Statistics 24 (IBM Corp., Armonk, NY) and MedCalc Statistical Software, version 18.10.2 (MedCalc Software bvba, Ostend, Belgium) were used for all statistical analyses. The median number of codes and distribution of codes for posts and comments were assessed, as well as the most frequent codes per year from 2013 to 2018. The years 2011 and 2012 were omitted in this temporal analysis of codes because of an insufficient number of posts and comments in each year.

We also assessed the median number of comments, the representation of self-identified HPs, median time to first comment, median time to first highly voted independent comment by an HP, and representation of posts mentioning a specific RT modality. We also analyzed the frequency with which the first comment on the post received the most votes.

**Results**

A total of 190 public posts about RT were posted by 178 unique users between February 2011 and May 2018. Almost all posts returned using our search terms discussed RT and thus were included in our database. A total of 468 replies by 295 unique users were also analyzed. For comparison, approximately 41,000 total posts were shared in [reddit.com/r/cancer](https://www.reddit.com/r/cancer). Thus, posts explicitly mentioning RT represent <0.5% of the total content on [reddit.com/r/cancer](https://www.reddit.com/r/cancer). Table 1 describes the criteria used to classify posts and comments by codes and provides examples of content for each code.

Figures 1 and 2 represent the most common codes for posts and comments, respectively; the size of the text correlates with the frequency with which the code appeared. The median number of codes per post was 4 (interquartile range [IQR], 4-5), and the median number of codes per comment was 3 (IQR, 2-4). Table 2 reports the most common codes for posts and comments. The most common organ system represented in both posts and comments was central nervous system (CNS) disease. The most frequent themes in posts were specific questions related to treatment, chronological accounts of the history of present illness, and treatment toxicities. A total of 125 posts (65.7%) included “treatment question,” 117 (61.6%) included “treatment chronology,” and 100 (52.6%) included “toxicities.” Exactly 44 posts (23.2%) included all 3 themes.

Tables E1 and E2 (available online at [https://doi.org/10.1016/j.adro.2019.01.007](https://doi.org/10.1016/j.adro.2019.01.007)) report changes in code frequency by year from 2013 to 2018 for posts and comments. We did not observe any noticeable differences in post or comment theme distribution over time.

Twenty-nine users (9.8%) were self-identified HPs, including 12 physicians (including 8 radiation oncologists) and 9 radiation therapists; however, HPs provided 26.5% of the highest voted comments and emerged in 42.5% of the top 3 comments. Exactly 48 of 181 top comments were contributed by HPs compared, with 45 of
Table 1  Descriptions of final codes

| Code                | Description                                                                                     |
|---------------------|-------------------------------------------------------------------------------------------------|
| Bone marrow transplant | Bone marrow transplant for malignancy                                                            |
| Brachytherapy        | Brachytherapy for malignancy                                                                    |
| Breast disease       | Primary breast disease or side effect at breast                                                   |
| Chemotherapy comparison | Comparing/contrasting radiation to chemotherapy                                               |
| CNS                 | Primary CNS disease or side effects at CNS                                                        |
| CyberKnife          | CyberKnife for malignancy                                                                       |
| EBRT                | EBRT not otherwise specified for malignancy                                                      |
| Family              | Referring to family (eg, for support or posting on behalf of family member)                     |
| Gammaknife          | GammaKnife for malignancy                                                                       |
| GI disease           | Primary GI disease or side effects at GI tract                                                  |
| GU disease           | Primary GU disease or side effects at GU tract                                                   |
| Lung disease         | Primary lung disease or lung side effects                                                        |
| Media               | Use of social media (eg, Facebook, YouTube, Instagram) or reference to news media               |
| Miscellaneous organ | Angiosarcoma, keloids                                                                            |
| Miscellaneous modality | Modalities not otherwise specified (eg, Cobalt-60, tomotherapy) for malignancy                  |
| Offering social support | Explicitly responding to emotional needs                                                        |
| Post-treatment       | Explicit reference to prior finished treatment                                                   |
| Proton therapy       | Proton beam therapy for malignancy                                                               |
| SBRT                | SBRT for malignancy                                                                             |
| Seeking social support | Explicitly stating emotional state or needs and requesting support                            |
| Social, economic, political | Content about socioeconomic or political aspects of cancer care (eg, financing, insurance, and health care reform) |
| Sharing information | Content predominantly offered for factual clarification (vs emotional support)                  |
| Skin disease         | Melanoma and nonmelanoma skin cancer primary disease or skin side effects                       |
| Treatment day motif  | Recurrent motifs associated with receiving radiation therapy (eg, radiation oncologist, catheters, and brachytherapy seeds) |
| Toxicities           | Side effects related to any oncologic treatment (eg, chemotherapy, radiation therapy)          |
| Treatment chronology | Clarification of history of present illness                                                       |
| Treatment question   | Question about treatment for factual clarification                                               |
| Whole brain radiation | Whole brain radiation for malignancy                                                             |

Abbreviations: CNS = central nervous system; EBRT = external beam radiation therapy; GI = gastrointestinal; GU = genitourinary; IGRT = image guided radiation therapy; IMRT = intensity modulated radiation therapy; SBRT = stereotactic body radiation therapy.

288 non–top comments by HPs (odds ratio, 1.95; 95% confidence interval [CI], 1.23-3.08; P < .0043). In total, 111 posts (58.4%) received a response from an HP. Additionally, 53 posts (27.9%) identified a specific RT modality, with proton therapy (7.4%), CyberKnife (5.3%), brachytherapy (4.2%), and whole brain radiation (4.2%) being the most common. Table 3 reports the distribution of self-identified HPs, represented with examples of high-quality comments by HPs. Table 4 reports the distribution of references to specific RT modalities.

The median number of comments per post was 9.0 (IQR, 5.0-13.0). Among posts with comments (n = 181), the median time to the first comment after posting was 64.0 minutes (95% CI, 53.0-82.0), and the median time to the first highly voted comment from an HP was 264.0 minutes (95% CI, 153.5-427.9; U = 4123.5; P < .0001 2-tailed). In 120 posts (66.3%), the first comment on the post received the most votes.

Discussion

Social media analysis is a useful complement to traditional epidemiologic studies because individuals tend to reveal unique attitudes and behaviors when not directly surveyed.15 Online social networks are known to improve the quality of life for patients with cancer by providing communal support and factual information about the disease.15–17 An abundant literature exists about cancer communities on Twitter,18,19 Facebook,20 and
research about cancer discussion on Reddit is lacking despite its significant share of Internet traffic. Therefore, we conducted a retrospective survey of posts and comments about RT on reddit.com/r/cancer. We observed that posts that directly reference RT comprised <0.5% of all posts on the subreddit, highlighting substantial opportunity for radiation oncologist involvement in this medium.

Post content

The most common post themes were questions related to treatment, chronological accounts of the history of the present illness, and treatment toxicities. Our interpretation of these findings is that posters want to provide readers with as much detail as possible to facilitate well-informed responses to questions and concerns. This demonstrates several advantages that Reddit offers for patients with cancer over similarly popular social media platforms. First, a Reddit post allows for substantial detail with 40,000 characters compared with 280 on Twitter and 2200 on Instagram. Indeed, many users took advantage of this opportunity by providing multiple-paragraph oncologic histories, including histology, imaging, goals of care, and other aspects spanning several years. Additionally, because Reddit only requires a (potentially disposable) e-mail address to sign up, it allows for significant anonymity, allowing patients to more easily share emotionally charged and potentially sensitive content. For example, multiple users took the opportunity to write cathartic narratives about well-intentioned but frustrating individuals they encountered throughout their course of treatment.

We postulate that CNS disease emerged as the most common organ system mentioned because symptoms related to CNS involvement (eg, seizures, personality changes, and impaired cognition) are highly distressing and likely to be noticed by patients as well as friends and family, prompting advice-seeking behavior on the Internet. In contrast, symptoms that involve other organ systems, such as gastrointestinal upset, dyspnea, or fatigue, may be more easily masked. We also observed that, although only 22.1% of posts included explicit appeals for social support, 37.1% of comments offered social support to the poster, highlighting an atmosphere of empathy and inclusion in the cancer subreddit.

A substantial number of posts and comments referenced family, either as a means of personal support or in the context of making a post on Reddit on behalf of a family member. This is consistent with Reddit’s demographics and the epidemiology of cancer. In total, 64% of Reddit users are between the ages of 18 and 29 years, 29% between 30 and 49 years, 6% between 50 and 64 years, and 1% 65+ years. Because older age is a significant risk factor for many cancers, it is unsurprising that Reddit users—who are more likely to be younger—are seeking advice on behalf of older friends and family, who are less likely to use the website.

Most posts did not explicitly reference any specific RT modality, but the single most common one referenced was proton beam therapy (PBT). This was surprising given the relative infrequency of PBT use compared with other modalities referenced (eg, CyberKnife and brachytherapy). We postulate that this is due to several factors. First, PBT is a relatively underused modality, but its utilization has been recently increasing at a rapid pace. Additionally, existing literature has demonstrated aggressive, controversial online marketing practices for PBT. Notably, 5 posts (35.7%) that referenced proton therapy were links to news articles about proton therapy (eg, why proton beams are more accurate than x-rays in treating cancer) with 0 to 2 comments, whereas other modalities were overwhelmingly represented in full-length posts in the context of patient narratives.

Considering these findings, we point to previous work demonstrating that websites about PBT frequently contain direct-to-consumer advertising for disease sites not...
endorsed by international consensus guidelines, as well as appeals to emotions using unsubstantiated claims of improved disease control and fewer toxicities.30

Table 2  Post and comment code distribution

| Code                  | Frequency | Percent |
|-----------------------|-----------|---------|
| Treatment question    | 126       | 14.6    |
| Treatment chronology  | 118       | 13.7    |
| Toxicities            | 103       | 11.9    |
| Treatment day motif   | 65        | 7.5     |
| Family                | 59        | 6.8     |
| Seeking social support| 42        | 4.9     |
| Sharing information   | 37        | 4.3     |
| CNS disease           | 32        | 3.7     |
| Chemotherapy comparison| 31      | 3.6     |
| Media                 | 31        | 3.6     |
| Head/neck disease     | 29        | 3.4     |
| Social, economic, political| 25 | 2.9 |
| Lung disease          | 19        | 2.2     |
| GU disease            | 18        | 2.1     |
| Breast disease        | 16        | 1.9     |
| Proton therapy        | 14        | 1.6     |
| Hematologic disease   | 13        | 1.5     |
| Gynecologic disease   | 11        | 1.3     |
| Gastrointestinal disease| 10    | 1.2     |
| Post-treatment        | 10        | 1.2     |
| CyberKnife            | 9         | 1.0     |
| Whole brain radiation | 8         | 0.9     |
| Brachytherapy         | 7         | 0.8     |
| Humor                 | 7         | 0.8     |
| GammaKnife            | 5         | 0.6     |
| SBRT                  | 4         | 0.5     |
| Miscellaneous organ   | 3         | 0.3     |
| Skin disease          | 3         | 0.3     |
| EBRT                  | 2         | 0.2     |
| IMRT                  | 2         | 0.2     |
| Miscellaneous modality| 2        | 0.2     |
| Bone marrow transplant| 1         | 0.1     |

| Code                  | Frequency | Percent |
|-----------------------|-----------|---------|
| Sharing information   | 357       | 24.4    |
| Toxicities            | 204       | 14.0    |
| Offering social support| 174     | 11.9    |
| Treatment chronology  | 135       | 9.2     |
| Treatment day motif   | 122       | 8.3     |
| Family                | 71        | 4.9     |
| Treatment question    | 59        | 4.0     |
| CNS disease           | 49        | 3.4     |
| Chemotherapy comparison| 38       | 2.6     |
| Head/neck disease     | 35        | 2.4     |
| Social, economic, political| 27   | 1.8     |
| GI disease            | 18        | 1.2     |
| GU disease            | 15        | 1.0     |
| Breast disease        | 14        | 1.0     |
| CyberKnife            | 14        | 1.0     |
| Humor                 | 14        | 1.0     |
| Proton therapy        | 14        | 1.0     |
| Lung disease          | 13        | 0.9     |
| GammaKnife            | 11        | 0.8     |
| Hematologic disease   | 11        | 0.8     |
| SBRT                  | 10        | 0.7     |
| Whole brain radiation | 10        | 0.7     |
| IMRT                  | 9         | 0.6     |
| Media                 | 9         | 0.6     |
| Miscellaneous organ   | 7         | 0.5     |
| Brachytherapy         | 4         | 0.3     |
| Gynecologic disease   | 4         | 0.3     |
| Skin disease          | 4         | 0.3     |
| EBRT                  | 2         | 0.2     |
| Bone marrow transplant| 3         | 0.2     |
| IGRT                  | 1         | 0.1     |

Abbreviations: CNS = central nervous system; EBRT = external beam radiation therapy; GI = gastrointestinal; GU = genitourinary; IMRT = intensity modulated radiation therapy; SBRT = stereotactic body radiation therapy.

Patient-provider interactions

We observed that, although HPs generally take longer to respond to posts, the top comments are more likely to be written by HPs. We interpret this finding as HPs taking more time to write deliberate, researched answers based on patient history. This may be partially explained by the fact that many self-identified HPs are frequent posters on the subreddit and thus have a reputation to uphold. The community appears to value these responses because top comments were significantly more likely to be written by HPs. It may also be possible that HPs commented on the posts without formally identifying as such (eg, out of additional concerns for preserving anonymity). We hypothesize that such users likely contributed some of the highly voted, well-reasoned comments with cited sources, thus possibly underestimating the effect sizes in our statistical analysis between HPs and non-HPs.

The aforementioned anonymity also allows providers to directly interact with patients using a more informal persona without fear of compromising their professional identities, which is a feature eagerly used on other websites, such as Sermo and Student Doctor Network.5 At the same time, providers generally adopted a professional tone and provided patients with nuanced explanations of the natural histories of their diseases, as well as cautious reassurance when appropriate (Table 3; eg “You cannot get inflammatory bowel disease or Celiac’s disease from radiation”). However, when faced with ambiguity, HPs tend to err on the side of caution and used a low threshold of suspicion for the
recommendation to see an HP in person. Providers also posted disclaimers about the limitations of their online patient interactions in the absence of a detailed clinical examination. Nonetheless, although HPs explicitly endorsed that their online recommendations were no substitute for a formal, in-personal evaluation by a provider, patients should be aware that anonymity does not allow for accountability.

Our findings recapitulate previous work showing that HPs use the Internet to directly engage with patients, rather than simply providing educational materials aimed at a broad, nonspecific audience. We observed a median time of approximately 4.5 hours to an HP response of high quality, as assessed by peer rating through the voting system. This free online reassurance about a concerning but ultimately benign symptom may provide significant

| Health care professional                                | Frequency | Example of highest-voted comment                                                                                                                                                                                                 |
|---------------------------------------------------------|-----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Radiation therapist                                     | 9         | “Radiotherapy treatments with cyberknife are one of the most precise treatments nowadays, the main goal is to irradiate small volumes while sparing the healthy tissue so the toxicity of the treatment is quite low…” |
| Physician-radiation oncology                            | 7         | “Many of these things are possible and do sound scary, but the chances of them happening/dramatically interfering with life is not very high. Some of them are not possible. For example, you cannot get inflammatory bowel disease or Celiac’s disease from radiation; some of the symptoms may be similar between possible (not guaranteed or likely) radiation effects and IBD or Celiac’s…” |
| Medical physicist                                       | 2         | “I am a trained radiotherapy medical physicist… Stereotactic radiosurgery (the technique Gamma Knife uses) does not remove the tumors from the brain, it simply slows down, stops, or reverses the growth of the tumors. It is very highly focused, so damage is only done to the tumors, not the surrounding normal tissue…” |
| Caregiver                                                | 1         | “…We have a cookbook “Eating Well Through Cancer.” My wife initially dropped 37 pound due to chemo destroying her appetite and GI tract. After bottoming out below 90 pounds she’s gained back 10, mostly by making sure she is getting protein and calories…” |
| Clinical epidemiologist                                  | 1         | “Hi, with 5-year survival rates around 96% for these types of cancers, either surgery alone or radiation alone are the standard treatment choices, with RT showing equivalent survival but fewer complications and adverse effects. No benefit would come with cyberknife or IMRT for these patients, so I think your uncle is getting the most reasonable option…” |
| Genetic counselor                                        | 1         | “The RAD50 genes are very new with little understood about them. Nccn has not even made any recommendations about what to do in patients with it. Your radiologist should have never ordered testing without pretest counseling but that’s changed now…” |
| Nurse                                                   | 1         | “Medicare covers the therapy. I would think, depending on the plan, the out Of pocket would be a percentage plus cost of commute and Meds. It’s hard to get a number as facilities bill at different rates at different areas…” |
| Pharmacist                                               | 1         | “I had a patient with vestibular Schwannoma who got radiation therapy for it. I think vestibular Schwannoma, which essentially never metastasizes, isn’t malignant but I know this is controversial…” |
| Physician-bone marrow transplant                        | 1         | “Consolidation chemotherapy has not been shown to improve outcomes in non-resectable stage IIIA NSCLC treated with concurrent chemoradiation…” |
| Physician-hematology/oncology                            | 1         | “[Proton therapy] isn’t proven to be any better, and often isn’t even proven to be as good for almost all cancers. I would recommend it for childhood brain tumors or other cancers near the brain or spinal cord, but that’s about it…” |
| Physician-neurosurgery                                   | 1         | “Are they certain of the diagnosis? A lot of this doesn’t make perfect sense. A 52yo person with a new glioma is almost never a grade 2, radiation necrosis almost never happens in a month, and even excellent neuroradiologists have great difficulty separating radiation necrosis from recurrent high-grade tumor on imaging alone…” |
| Physician-pathology                                     | 1         | “That’s a bad situation. From how you describe it, I wonder if no one saw how delirious she is. Imaging can usually suggest recurrence or residual tumor growth, and sometimes a biopsy is only done to confirm suspicions…” |
| Physician-radiation oncology/palliative care             | 1         | “Brachytherapy is a very effective treatment for some categories of prostate cancer. Prostate cancer can usually be followed very well with the PSA blood test after this procedure. It can take a couple of years though for the PSA to reach its lowest levels after brachy, and then it is monitored for many years after that to determine if it is staying down…” |
| Radiation therapy student                                | 1         | “I’m an rt student and we have a cyber knife in our department. I might be able to answer a few questions:)” |
Table 4 Distribution of posts referencing specific radiation therapy modalities

| Modality                                 | Frequency | Percent |
|------------------------------------------|-----------|---------|
| Proton therapy                           | 14        | 7.4     |
| CyberKnife                               | 10        | 5.3     |
| Brachytherapy                            | 8         | 4.2     |
| Whole brain radiation                    | 8         | 4.2     |
| GammaKnife                               | 5         | 2.6     |
| Stereotactic body radiation therapy      | 4         | 2.1     |
| External beam radiation therapy          | 2         | 1.1     |
| Linear accelerator                       | 2         | 1.1     |
| Bone marrow transplant radiation         | 1         | 0.5     |
| Cobalt-60                                | 1         | 0.5     |
| Intensity modulated radiation therapy    | 1         | 0.5     |
| Tomotherapy                              | 1         | 0.5     |

relief, but as mentioned, providers recommended a low threshold for seeing HPs in person.

Additionally, many patients have the option of calling their physicians’ personal phones at a moment’s notice with questions and concerns, but patients are often reluctant to reach out to their providers for concerns of “low perceived need” for interpersonal reasons, such as guilt or inconvenience. These sentiments were echoed in our data (eg, “...since my case isn’t very serious I try not to take up much of [my doctor’s] time and sometimes just being nervous I forget to ask questions but rather just agree...”).

Of note, although Reddit allows patients to quickly obtain reassurance and guidance from self-identified HPs, there is no guarantee of expertise behind the response received. An in-person visit may exact a significant financial burden on patients, but it generally provides a guarantee of being evaluated by a board-certified or board-eligible professional, which is not seen on this social media platform, because there is no formal verification process for self-identified HPs. Nonetheless, although there is a risk of misclassification of HPs, comments with factual inaccuracy or opportunities for alternative courses of action (eg, “trust your oncologist” vs “seek a second opinion”) frequently received responses with cited sources and detailed reasoning.

Limitations

This study has several important limitations. First, as mentioned, Reddit’s demographics have several important differences compared with those of the general population, mainly with regard to age. Moreover, 60% to 70% of Reddit users are men, and >80% have completed some college education. However, there are also significant variations between Reddit’s average demographics and those of individual subreddits. We hypothesize, for example, that the cancer subreddit likely has a greater proportion of oncologists than the website as a whole. As such, Reddit may be less useful to patients with limited education or computer literacy, and several of the cultural references in conversations may be missed because of intergenerational differences. We also limited our analysis to reddit.com/cancer. Although this is the most popular subreddit to discuss cancer by orders of magnitude (at 20,600 subscribers), other subreddits such as r/radiation-oncology (191 subscribers), r/breastcancer (1,500 subscribers), and r/I Survived Cancer (443 subscribers) contain additional posts about RT. However, when queried with the same search terms used for r/cancer, the content of returned posts was largely similar to that of r/cancer. Thus, we believe our sampling of reddit.com/r/cancer alone is representative of posts about RT among patients with cancer on Reddit.

Additionally, Reddit’s voting system has previously been criticized for biasing the first comment on posts such that submission time disproportionately affects the final number of votes received. Indeed, we observed that in 120 posts (66.3%), the first comment on the post received the most votes. Nonetheless, most top comments we observed included detailed responses by HPs in response to specific concerns by patients and their families. We also used manual coding per author consensus in this study, although existing work reports that this appears to outperform algorithmic methods for classifying thematic content in social media.

Conclusions

Given these findings, we believe that HPs, particularly those already engaged with social media, should consider adding Reddit to their repertoire for patient outreach. At the very least, we advocate periodic monitoring of the website because only 9.8% of posters in our sample were self-identified HPs, and the anonymity the website affords comes at the cost of accountability. Current radiation oncologist involvement on reddit.com/r/cancer is small, but we believe that traffic will likely increase with the 2017 ASTRO social media initiative, highlighting significant opportunity in the here-and-now to engage with patients on this platform. Specific opportunities include radiation oncology professionals becoming verified or openly identifying themselves online and conducting Ask Me Anything, ASTRO, or ARRO hosting threads to provide evidence-based discussion in dedicated subreddits (r/cancer, r/medicalschool, r/breastcancer), and possibly even the use of an official organizational handle to post verified and peer-reviewed material on Reddit with which others could engage.

Supplementary data

Supplementary material for this article can be found at https://doi.org/10.1016/j.adro.2019.01.007.
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