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Fears and Misperceptions of Radiation Therapy: Sources and Impact on Decision-Making and Anxiety

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Abstract Recent media attention about radiation has led to heightened public awareness and concern about radiation therapy (RT). An understanding of concerns and their potential role in patient decision-making can inform education efforts. A multiphase needs assessment survey was designed to ascertain broad public perceptions of radiation (phase I) and the more in-depth cancer patient perceptions of RT (phase II). One hundred forty-six phase I and 111 phase II surveys were completed. Data suggested a prevalence of negative connotations of the word "radiation," often associated with information from the media or secondhand experience. Side effects during and after RT were reported as concerns, including misperceptions about becoming radioactive and impact on fertility. Rankings of quality and safety perceptions suggested confidence in staff training and equipment, though concerns regarding overdoses and protection of healthy tissue were higher amongst those who refused RT. In deciding whether or not to undergo RT, high value was placed on the reputation of the cancer centre and the expected effectiveness of RT. The importance of understanding RT was more highly regarded by those who underwent RT than those who refused it. Perceptions of RT should thus be addressed amongst those in a position to consider RT, to maximize RT utilization where appropriate.

Keywords Radiation therapy patient · Education · Decision-making · Fear of radiation

Introduction

Many Canadian cancer patients are not accessing an effective treatment modality. Radiation therapy (RT) is underutilized in Canada, even when indicated [1, 2]. While much of the shortfall in utilization can be attributed to health systems factors, including wait times and referral patterns [3], it is important to acknowledge the potential impact of patient fears and misconceptions regarding RT. Patient knowledge and trust have been noted to be significant factors in the underuse of RT [1], with misinformation found to lead to anxiety [4]. Recent publications on medical error in RT as well as nuclear disasters such as in Fukushima in 2011 have led to increasing media attention to radiation quality and safety issues and heightened public awareness regarding radiation and its use in cancer treatment [5, 6].

By assessing the scope and focus of patient concerns with respect to quality and safety issues in RT, educational efforts can be directed towards addressing these concerns [7, 8], thus reducing the fear and anxieties relating to RT and potentially the number of patients who refuse RT based on misguided beliefs or anxieties [9, 10].

Materials and Methods

A multiphase study was undertaken as a needs assessment to ascertain broad public perceptions of radiation (phase I) and the more in-depth cancer patient perceptions of RT (phase II).

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Phase I: Public Survey

Study Population and Sample Size

The phase I study population was drawn from two cancer charity athletic events. This group represented a convenience sample of anyone who might have participated in the events or attended to show their support; informed public, health professionals, and some patients and their family members.

Survey Tool

A short eight-item "informed public" survey, consisting primarily of Likert scale and multiple choice items, was developed by investigators specifically for this study, with additional insight from other subject matter experts in RT patient education. As well as basic demographics, question domains included immediate perceptions of the word 'radiation', and factors thought to contribute to the decision to have or not have RT as a treatment modality if offered. Items were chosen based on investigators' understanding of common concerns and misperceptions about radiation. A draft survey was reviewed by a broader group of subject matter experts for preliminary content validity.

Recruitment and Dissemination

Paper copies of the survey were administered by research assistants (RAs) at each of two cancer charity athletic events. With the permission of the event organizers, RAs approached event participants, spectators, and volunteers with clipboards and invited them to complete the short survey.

Data Collection and Analysis

Data from paper surveys were collected by RAs and entered into SPSS® (IBM), generating primarily descriptive statistics. Coding of free-text responses, namely the word associations, was done independently by three investigators, and discrepancies in assignment to established categories were addressed through consensus-generating discussion and recoding.

Phase II: Patient Survey

Study Population and Sample Size

Participants were sought from within two patient populations; one being a single major cancer centre that sees over 12,500 new patients annually, and the other being a broader electronic patient network of over 300 email addresses, managed within the same institution. Criteria were that the participants could read and understand English, had a diagnosis of cancer, and may or may not have undergone RT. No restrictions were made as to cancer disease site, stage, or point in the process of care.

Survey Tool

A 20-item "patient survey," consisting of multiple choice and Likert scale items was developed specifically for this study. A number of question domains from the phase I survey were also employed in this tool, with additional domains regarding health status and history, anxiety, and concerns regarding RT (including safety and side effects), access to information regarding RT, and perceptions of safety and quality assurance in RT.

Recruitment and Dissemination

Paper Survey Paper copies of the survey were distributed in ambulatory waiting areas at the hospital. RAs circulated regularly over the 6-week period to encourage and facilitate completion of the survey. A collection box was left in each area.

Electronic Survey An electronic version of the survey was created and remained active for the same 6-week period. Poster advertisements were posted in common areas of the hospital, highlighting a survey link. The link was also disseminated through an institutional Virtual Patient Focus Group (VPFG). The VPFG constitutes a network of patients from within the single institution and their family members who have expressed interest in participating in periodic surveys through an e-mail distribution list. The list contains over 300 email addresses, and the background, eligibility criteria, and survey link were sent out by the VPFG administrators at the start of the study period.

Data Collection and Analysis

Completed paper surveys were collected regularly from ambulatory waiting areas, and data were input manually into an electronic database by study investigators. Data collected online were exported into the same database, with coding used to identify online versus paper submissions.

Data were analyzed using SPSS® (IBM), generating primarily descriptive statistics. For questions using the five-point Likert scale, rankings of 1 or 2 were considered to be in disagreement with the statement, while rankings of 4 or 5 were considered to demonstrate agreement. A feeling of neutrality was assigned to items ranked as a 3.

Results

Phase I: Public Survey

A total of 146 public surveys were completed. Seventy-one (48.6 %) respondents identified themselves as female. Only four (2.7 %) identified themselves as cancer survivors and nine (6.2 %) as health professionals. Other respondents constituted event participants, spectators, and volunteers, with a number of people identifying themselves as belonging to multiple categories.

A total of 152 words/phrases were listed when respondents were asked what came to mind when they read the word 'radiation' (Table 1). Twenty-two words were reported more than once, with "cancer" being the most frequent response (*n*=40). The majority of these words (60.5 %, *n*=92) conferred a neutral connotation of radiation, 50 words (32.9 %) conferred a negative connotation, and the remaining 10 words (6.6 %) were positive. The proportion of responses provided by those identifying as patients and health professionals are also included in Table 1.

When asked what experience might have contributed to their initial word association, almost half of all words (46.1 %, *n*=70) were attributed to the experience of a friend or family member (Table 2). Personal experience, TV/movies, and media coverage were deemed to have played less of a role in associations. Personal experience or that of a friend or family member tended to generate more positive associations than did media coverage or TV/movies, though significance was not assessed

Phase II: Patient Survey

Demographics

A total of 111 surveys were submitted (72 hard copy, 39 online). Seventy-one (66.4 %) respondents identified themselves as female. The median time since diagnosis was 33 months (interquartile range=62 months). The two most common cancer sites were breast (32 (28.8 %)) and GU (14 (12.6 %)) malignancies. Eighty-two (73.9 %) respondents indicated that they had or were currently are undergoing RT, 20 (18.0 %) were never offered RT, and 9 (8.1 %) were offered RT but refused this modality of treatment.

Perceptions of Quality and Safety in RT

Respondents were most likely to be concerned about side effects after treatment (81.2 %, *n*=82) and during treatment (77.8 %, *n*=77) (Table 3). When looking at selected more specific concerns, fatigue was a concern to a majority in all groups. Of least concern were radiation's effect on patient fertility and risk to family or friends of becoming radioactive, at 18.8 % (*n*=13) and 14.3 % (*n*=13), respectively. Risks to fertility, of becoming radioactive, and of accidental overdose appeared to be of greater concern to those who refused RT, but the limited response rate from this group precluded assessment of significance.

When asked about the degree of confidence in the quality and safety of RT, 91.8 % (*n*=90) agreed that the health-care team involved in radiation treatments is well-trained (Table 4). It was also agreed (89.2 % (*n*=91)) that efforts are always being made to improve RT treatment. Patients indicated the least amount of confidence in the safety and protection of their healthy tissues from radiation, with fewer than half (46.0 %, *n*=46) being confident in this. Confidence was lowest for this item amongst those who refused RT (12.5 %, *n*=1).

Sources of Information about RT

Hospital resources were the most frequently acknowledged source of information in developing perceptions about RT (85.7 %, *n*=78) (Table 5). Internet searches (67.1 %, *n*=57)

Table 1 Associations with the word 'radiation'

	Total (*n*=152)	No. (%) from patients	No. (%) from health professionals	Themes	Examples of specific words
Positive	10 (6.6 %)	0/10 (0)	2/10 (20.0)	Healing (6)	"Healing," "cure"
				Other (4)	"Courage," "life"
Negative	50 (32.9 %)	1/50 (2.0)	2/50 (4.0)	Side effects (21)	"Burn," "hair loss," "tired"
				Fear (7)	"Fear," "scary"
				Pain (7)	"Pain," "painful"
				Other (15)	"Temp fix," "poison"
Neutral	92 (60.5 %)	3/92 (3.3)	5/92 (5.4)	Treatment (23)	"Treatment," "therapy"
				Cancer (42)	"Cancer," "tumor"
				Nuclear power (9)	"Nuclear," "nuclear power"
				Other (18)	"Glow," "cell phone," "zap"

Table 2 Factors contributing to associations with the word 'radiation'

	Positive, n=10 n (%)	Negative, n=50 n (%)	Neutral, n=92 n (%)	Total, n=152 n (%)
Personal experience	5 (50.0)	5 (10.0)	30 (32.6)	40 (26.3)
Experience of family/friend	4 (40.0)	25 (50.0)	41 (44.6)	70 (46.1)
TV/movies	0 (0)	13 (26.0)	10 (10.9)	23 (15.1)
Media coverage	1 (10.0)	7 (14.0)	11 (12.0)	19 (12.5)

and people who had already undergone RT (66.3 %, n=53) were both found to be valuable sources of information. The media was found to be the least agreed upon source, with only 27.2 % (n=22) indicating that it aided in their understanding of RT. Only two sources of information were more predominantly recognized by those who had RT than by those who refused it: scientific literature and health professionals.

Factors in Decision to Have or Refuse RT

Of all presented considerations in the decision to undergo RT, respondents were most likely to rank the reputation of the RT centre (92.5 %, n=49) and the expected effectiveness of RT (81.5 %, n=66) as being of importance (Table 6). Two thirds of respondents also acknowledged the role in decision-making of both information on RT and understanding how RT works. Least likely to be considered factors were the potential for side effects or radiation exposure.

Discussion

Fear, anxiety, and misunderstanding of RT are prevalent amongst cancer patients and the public, and may constitute a barrier to patients consenting to treatment, even if this modality is clinically indicated [11, 12]. Currently, the extent to which this barrier plays a role in the Canadian context has not been adequately studied [3]. Radiotherapy is often unknown to patients before it is recommended to them [13], with 78 % of respondents in one study rating their understanding on external beam RT as "a little bit" or "not at all" [14]. Consequently, treatment decisions may be influenced by widely held negative associations with the broader concept of radiation [15, 16].

Despite the potential that the sample population in phase I of this investigation, polled at a cancer fundraising event, was more aware or educated regarding cancer treatment options, associations with radiation were rarely positive This was especially true amongst those who cited the media, TV, and movies as their primary sources of information. Among the patients surveyed in phase II, the Internet was the most commonly cited nonmedical source of information, with 67 % indicating that it had contributed to their perception of radiotherapy. Preliminarily, it also appears that patients who had refused RT were more likely than others to cite the media, TV, movies, and the Internet as sources of information. These results support the findings of others who have argued that mass media reports can create negative perceptions of radiation as well as fear and anxiety amongst patients [16–18]. Lay information found on the internet may be an increasingly prominent influence on patient perceptions of radiation, as a Pew study found that while a growing majority of American Internet users search online for health-related information, very few check the source and date of the information they retrieve [19].

Mass media may contribute to patient fears of RT by familiarizing the public with nuclear power and atomic weaponry while leaving them relatively uninformed on medical applications of radiation. The public surveyed here used words such as "burn" and "poison" when associating with

Table 3 Concerns regarding the potential side effects of RT

I have concerns relating the safety and possible effects of radiation therapy in the following areas:		% (n) with concerns about the following as potential side effects of RT			
		Had RT	Refused RT	Not offered RT	Total
General	Side effects *during* RT in the treatment area	78.7 (59/75)	66.7 (4/6)	77.8 (14/18)	77.8 (77/99)
	Side effects *after* RT in the treatment area	81.8 (63/77)	83.3 (5/6)	77.8 (14/18)	81.2 (82/101)
Specific	Fatigue	69.3 (52/75)	66.7 (4/6)	77.8 (14/18)	70.7 (70/99)
	Radiation causing a new cancer	49.3 (37/75)	40.0 (2/5)	47.4 (9/19)	48.5 (48/99)
	Effect of radiation on fertility	17.7 (9/51)	40.0 (2/5)	15.4 (2/13)	18.8 (13/69)
	Risks to my family or friends if I become radioactive	14.7 (10/68)	28.6 (2/7)	6.3 (1/16)	14.3 (13/91)
	A radiation overdose due to an error or accident	27.4 (20/73)	60.0 (3/5)	27.8 (5/18)	29.2 (28/96)

Table 4 Confidence in quality and safety of RT

I am confident that:	% (*n*) confident in the following aspects of RT quality and safety			
	Had RT	Refused RT	Not offered RT	Total
Radiation therapy is always delivered safely	69.9 (51/73)	75.0 (6/8)	65.0 (13/20)	69.3 (70/101)
Efforts are always being made to improve quality in the delivery of radiation therapy	90.5 (67/74)	75.0 (6/8)	90.0 (18/20)	89.2 (91/102)
My healthy tissues and organs are protected from radiation	49.3 (36/73)	12.5 (1/8)	47.4 (9/19)	46.0 (46/100)
The equipment used to deliver treatment is safe	74.3 (55/74)	50.0 (4/8)	75.0 (15/20)	72.5 (74/102)
The prescription and plan for radiation treatment decided for me are correct	69.4 (50/72)	42.9 (3/7)	68.8 (11/16)	67.4 (64/95)
The health-care team involved in my radiation treatment is well-trained to do their job	91.9 (68/74)	85.7 (6/7)	94.1 (16/17)	91.8 (90/98)

radiation, and a previous study found that patients' most common nonmedical association with radiation was "the atom bomb" [16]. High-profile reports on radiation treatment incidents appearing in the news may also have an impact on public perception and contribute to patient fear [5, 6]. Nearly 30 % of patients surveyed in this investigation expressed concern that they may receive a radiation overdose due to an error or accident.

The predominantly negative associations with radiation found in this sample of the Canadian public are consistent with literature from several other developed countries, suggesting that an "image problem" exists for RT internationally. A wide-ranging survey in the UK found that fewer than 10 % of respondents perceived radiotherapy as a "modern cancer treatment" [12], and a US study reported no change in radiotherapy refusal rates between 1988 and 2005 despite great improvements in the safety, efficacy, and number of treatment options available [2]. A German review of risk perception regarding diagnostic and therapeutic procedures that employ radiation concluded that patients frequently make treatment decisions based on partial or incorrect information [17].

Given that many patients may be fearful or lack knowledge of radiation when entering the system, accessible and informative patient education resources are invaluable. Many existing resources have proven effective in improving treatment-related knowledge and in reducing anxiety and distress [14, 20–22] However, not all patient education resources achieve their objectives [10], and great variety in the timing and delivery of patient education can still exist between radiation oncology departments [8]. This makes it difficult to draw firm conclusions about the optimal timing of delivery of these interventions. In this study, 14 % of patients expressed concerns about risks to their loved ones through becoming radioactive. Given that this can only be a valid concern for patients receiving brachytherapy or radioactive iodine treatment, it can be inferred that important misconceptions about the risks of treatment exist among both those who received radiotherapy and those who refused. In another study of patients recommended for radiotherapy, 91 % reported understanding the difference between external beam radiation and brachytherapy "a little bit" or "not at all" [14]. This suggests a shortcoming in either the content or the method of provision of information guiding treatment decision-making. Several other studies have also demonstrated significant shortcomings in patient understanding of their radiation treatment [4, 14, 16, 23]. In interviews conducted by Hammick et al. in the UK, 40 % of patients who had already undergone treatment could not explain their understanding of the word radiation [16].

Table 5 Sources of information

	% (*n*) recognizing each source of information as having contributed to their perception of RT			
	Had RT	Refused RT	Not offered RT	Total
Media coverage (newspaper)	23.2 (13/56)	50.0 (4/8)	29.4 (5/17)	27.2 (22/81)
TV/movies	14.8 (8/54)	62.5 (5/8)	21.4 (3/14)	28.6 (16/76)
Internet	63.8 (37/58)	75.0 (6/8)	64.3 (9/14)	67.1 (57/80)
Scientific literature	64.4 (38/59)	50.0 (4/8)	50.0 (7/14)	60.5 (49/81)
Peer who underwent RT	63.6 (35/55)	85.71 (6/7)	66.7 (12/18)	66.3 (53/80)
Friend/family	44.0 (22/50)	57.1 (4/7)	68.8 (11/16)	50.7 (37/73)
Hospital information	88.4 (61/69)	100.0 (7/7)	66.7 (10/15)	85.7 (78/91)
Health professional	86.7 (60/69)	80.0 (4/5)	76.5 (13/17)	84.6 (77/91)

Table 6 Factors involved in RT treatment decision

The following factors contributed to my decision to have or not to have radiation therapy:	% (*n*) who considered the following to be a factor in their decision-making			
	Had RT	Refused RT	Not offered RT	Total
Distance to travel to a radiation treatment centre	49.0 (25/51)	0.0 (0/3)	25.0 (1/4)	44.8 (26/58)
Amount of available information about radiation therapy	66.7 (44/66)	50.0 (2/4)	60.0 (3/5)	65.3 (49/75)
Time needed to complete all radiation treatments (often 5–6 weeks of daily treatment)	47.6 (30/63)	0.0 (0/3)	33.3 (2/6)	44.4 (32/72)
Expected side effects	27.3 (18/66)	25.0 (1/4)	33.3 (2/6)	27.6 (21/76)
Opinions of family and friends	51.7 (30/58)	0.0 (0/3)	20.0 (1/5)	47.0 (31/66)
Expected effectiveness of treatment	84.5 (60/71)	75.0 (3/4)	50.0 (3/6)	81.5 (66/81)
Other treatment options available	34.6 (19/55)	50.0 (2/4)	66.7 (4/6)	38.5 (25/65)
Fear of radiation exposure	15.9 (10/63)	33.3 (1/3)	20.0 (1/5)	16.9 (12/71)
Understanding how radiation therapy works	68.3 (43/63)	33.3 (1/3)	80.0 (4/5)	67.6 (48/71)
Reputation of radiation treatment centre	91.8 (45/49)	100.0 (2/2)	100.0 (2/2)	92.5 (49/53)

The importance of ensuring accurate, thorough, and accessible educational resources is further supported by the findings in phase II of this investigation that the majority of respondents reported "Understanding how radiotherapy works" as a factor involved in their treatment decision. This was outvalued solely by the reputation of the radiation treatment centre and the expected effectiveness of the treatment. Indeed, others have found that greater knowledge of radiation is associated with lower perceived treatment risks [24]. Qualitative interviews by Long et al. identified "being informed" as a key need for radiotherapy patients, which includes addressing fears based on incomplete or false information [18]. Penrod et al. [25] argued that such fears generate a state of "uncertainty" which they defined in part as a "dynamic state in which there is a perception of being unable to assign probabilities to outcomes." However, surveys conducted by Bolderston found that health-care professionals profoundly underestimated the importance to their patients of understanding RT treatment [7]. Taken together, these findings make a case for patient and public education that respects patients' need and capability to understand radiotherapy. This may be a crucial step in reducing the uncertainty that patients experience while weighing the benefits and risks of this treatment modality, thus empowering them to make more autonomous treatment decisions.

The timing and scope of radiotherapy education are also important to consider. This investigation suggested that those who underwent RT may have had persistent misconceptions never addressed through education. Almost one fifth of patients who made the decision to have RT nonetheless considered a fear of exposure as an important factor in their decision-making. While some RT patients will have legitimate concerns about these issues depending on their disease site and treatment plan, 17.7 % had fears about fertility, 14.7 % had fears about becoming radioactive, and 27.4 % were concerned about the safety of this treatment modality. At the other end of the spectrum, education that begins only at the time patients enter the radiotherapy system will be unable to reach patients who never attend a referral out of fear of radiation, or who never receive a referral due to a lack of radiotherapy awareness on the part of their physician. A study on referring physicians in northern Alberta showed a clear relationship between their knowledge of RT, both self-assessed and actual, and their referral rates for radiotherapy consultations [26]. A review by Freudenberg and Beyer concluded that health-care professionals outside of radiation medicine are commonly misinformed when it comes to radiation, and argued that "it must be a primary goal… to thoroughly educate future opinion shapers" [17]. Fostering a familiarity with RT in the public eye as well as among other health-care providers will empower future patients to make more informed and autonomous treatment decisions and may improve the ability of those in a position to refer for radiotherapy to help their patients make more informed decisions.

One significant limitation was the small sample population of those who had refused radiotherapy, limiting the ability to draw firm conclusions about the refusal of treatment. It is also likely that patient-specific factors play a role in therapy acceptance or refusal, and a much larger sample is warranted in order to determine whether high-need subgroups exist. These data do suggest that older patients may be more likely to refuse RT, and this hypothesis is supported by the findings of others [2, 27]. In an American sample, Hamidi and Moody found that older age as well as cancer site related to refusal rates for radiotherapy [2] and a larger study is needed to determine whether similar patterns exist in the Canadian context. Studies in Canada [28] and elsewhere [29] have suggested a relationship between cultural background and attitudes to radiotherapy; however, the present study was not able to investigate this potential patient variable due to the nature of the sample and the exclusion of non-English speakers.

Conclusions

While this study provides some insight into the perceptions and fears of RT in Canada, its findings should be viewed as preliminary and hypothesis-generating. This preliminary research suggests that public perceptions of radiation are rarely positive, especially when those perceptions are shaped by lay information. Many patients may have little initial understanding on radiation and radiotherapy, and so there is a risk that some may refuse treatment on the basis of incomplete or inaccurate information. However, patients consistently express the desire to understand their treatment options, and such understanding may be an essential first step in helping them to make informed decisions based on the actual risks and benefits associated with RT. Additional research is needed in order to better understand the needs and motivations of those who refuse RT in Canada, as well as to identify potential high-need subgroups of the patient population.

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