Evaluation of Patient Satisfaction in Outpatient Radiation Oncology Department

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Abstract

Purpose: Nowadays cancer patients want more detailed information and greater participation in decisions about their care. As a consequence, the demands on health care system to satisfy the complex care needs of oncology patients have increased tremendously.

Methods and Materials: As part of a quality improvement exercise at the Radiation Oncology department, Allan Blair Cancer Center, Regina, Saskatchewan, Canada, a survey was undertaken to ascertain the level of patient satisfaction with the information and care they were receiving from their care team during their first interaction with physicians till they finish radiation. In addition, the patients' anxiety levels during radiation were investigated as well. Both questionnaires were given to patients on first day of their radiotherapy and after the completion of their radiotherapy.

Results: Total of 122 patients were enrolled in the study and 100 of them both questionnaires pre and post radiation therapy. Majority of patients were satisfied with information they received regarding their illness (94%) and treatment toxicity (81%), but few less satisfied with the information they received regarding lifestyle issues such as diet, exercise, time off work, sexuality and smoking. The patients showed a statistically significant reduction in both their State and Trait Anxiety scores following radiotherapy ($p<0.001$). The results of the two-sample t-test were significantly lower in post radiation period (State trait $r = 0.521$, Anxiety trait $r=0.701$).

Conclusions: Research has established many barriers for proper communication. The initial meeting should be unhurried and there is a risk that contents may not be grasped so, there should be planned repetitions. Several repetitions and subsequent visits may be needed for a patient to hear what is said, respond to it, and retain this information in their mind.

Keywords: Patient Satisfaction, Radiation Oncology, Outpatient

Introduction

Satisfaction means contentment which is actually the experience of satisfaction and being at ease in one's situation. Contentment is the ultimate goal, which once achieved there is nothing to seek until it is lost. A living system cannot maintain contentment for very long as complete balance and harmony of forces is never possible. This remains true for our health system as well.

In the modern world, cancer is one of the leading causes of morbidity and mortality. It places considerable mental, physical and emotional stress on patients and their loved ones. It requires them to make major adjustments in their lives and many other key areas such as social, financial, spousal and many other commitments as a human being. As a consequence, the demands on health care system and providers to satisfy the complex care needs of oncology patients have increased tremendously. Of late, patient satisfaction has been recognized as one of the key indicators of health care quality and is now being used by many leading health care systems across the globe to monitor system efficiency, adequacy of existing programs, maintenance of accreditation and development of new marketing strategies.(1) Patient satisfaction information is also being used to compare and benchmark hospitals, identify best-performance institutions and discover areas in need of improvement. However, the existing literature on patient satisfaction, as it relates to quality of cancer care is highly inconsistent and heterogeneous. There are differences in study designs, questionnaires, study populations and sample sizes. This has led to disparity among practicing oncologists hence no consensus regarding this vital issue exists.

The aim of the present study was to evaluate the satisfaction of cancer patients, undergoing radiotherapy regarding the care and information received during their radiation treatment period.

Material and Methods

As part of a quality improvement exercise at the Radiation Oncology department in Allan Blair Cancer, Center, Regina, Saskatchewan, Canada, a survey was undertaken to ascertain the level of patient satisfaction with the information and care they were receiving from their treating radiation oncologist and the care team from their first interaction with physicians until conclusion of radiation treatment. In addition, the effect of radiation on patients' anxiety levels was investigated as well. Two questionnaires were given to patients undergoing external beam radiation for any histologically, proven malignancy. The first questionnaire was the Information Satisfaction Questionnaire (ISQ) and the second questionnaire was the State Trait Anxiety Index (STAI).Both questionnaires were given to the patients on first day of their radiotherapy after they received a teaching session with radiation technologists and after the completion of their radiotherapy. Both the STAI and the ISQ are validated instruments used for measuring patient anxiety and satisfaction.(2) The ISQ is available from the website www.cancernet.co.uk/questionnaire. The State Anxiety score is a measure of a patient's current level of anxiety at a particular point in time. It is most influenced by external stresses. The STAI Form Y is the definitive instrument for measuring anxiety in adults. It clearly differentiates between the temporary condition of "state anxiety" and the more general and long-standing quality of "trait anxiety". It helps professionals distinguish between a patient's feelings of anxiety and depression. The inventory's simplicity makes it ideal for evaluating individuals with lower educational backgrounds. Adapted in more than forty languages, the STAI is the leading measure of personal anxiety worldwide. The STAI has forty questions with a range of four possible responses to each. The Trait Anxiety score is a measure of a patient's inherent level of anxiety and is less influenced by external stresses occurring at any particular time and can be purchased from Mind Garden at www.mindgarden.com. Mind Garden is an independent publisher of psychological assessments and instruments. Their goal is to "preserve and grow" important psychological assessments. Mind Garden serves members of the academic, research, and consulting communities by offering high quality, proven instruments from prominent professionals.(3)

Results

A total of 122 patients were enrolled in the study and 100 of them completed the first and second questionnaire. The reasons for not completing the second questionnaire included having found the first questionnaire difficult, having their radiation schedule changed, death occurring before completion of radiation treatment and finally, not receiving their scheduled course of therapy because of disease progression.

The characteristics of patients who completed both the questionnaires are shown in Table- 1. Males and females were evenly distributed in the study population.

The most common primary cancer were breast and lung cancer which is compatible with Canadian cancer statistics.

Before initial consultation of the patients with the radiation oncologist, all patients had received some form of information regarding their malignancy. Contact was initiated within 5 days of receiving the referral at new patient's referral center by Patient Access Coordinator (PAC) prior to their first appointment. These specially trained social workers attempted telephone contact with each patient or their family member. Each attempted contact is documented in our computerized medical system (CMS).Three phone contact attempts without completions were considered sufficient.

Table- 1. Baseline demographic and clinical characteristics.

Variable	N (100)
Males	56
Females	44
Age in years < 65	42
Age in years> 65	55
Primary malignancy	
Lung	20
Breast	17
Gynae	05
Brain	04
Sarcoma	01
Head and Neck	02
Lower GI cancer	11
Upper GI cancer	05
Palliative	16
Other	19
English first language	87
Other languages	13
Clinical trial offered: Yes	12
Clinical trial offered: No	88
Chemotherapy: Yes	86
Chemotherapy: No	14
Do you know your illness: Yes	85
Do you know your illness No	15

During this interaction, the patient was provided with emotional support and information designed to assist them as they await their initial appointment with a medical or radiation oncologist. Patients were provided with contact information should they require further previsit support. At the same time, a letter was sent to the referring physician, notifying them of receipt of the referral and provision of PAC services. Each family receives information package covering general cancer topics, diet, volunteer drivers program and cancer lodge at their first appointment in the cancer clinic. The results of the information satisfaction questionnaire are shown in Table- 2. The majority of our patients were satisfied with information they received regarding their illness (94%) and treatment toxicity (81%). Patients felt that diagnosis of cancer and radiation treatment had a major impact on their active leisure pursuits and thus led to reduced participation in social and community activities.Patients wanted suggestions regarding new strategies for relieving tension, like yoga, meditation and exercise (80%). However our information package bag contains material on important issues such as distress, nutrition, parking and lodging. It includes a visiting card with social workers contact number if extra help is required. A significant number of patients (30%) thought it was too cumbersome to read and remember that material.

The results of the pre and post radiation STAI questionnaire are shown in Tables- 3.

Table- 2. Resultsof the information satisfaction questionnaire.

Information needs		No. (%)
1	All available information and to be involved in decision of illness.	94
2	Only positive information about illness	02
3	Only limited information and would prefer the doctor to decide	03
4	Only limited information would prefer family to decide	01
Satisfaction needs		
1	Explanation of illness	94
2	Explanation of toxicity	81
3	Discussion of lifestyle issues	41
4	Discussion of practical issues	56
5	Cumbersome to read material	30
6	Information material could be improved	25
7	Overall satisfaction to information received	95

Table- 3. Pre and post radiotherapy STAI scores.

Pre RT State anxiety	39.40
Pre RT Trait anxiety	35.06
Post RT State anxiety	31.06
Post RT Trait anxiety	31.09

Table- 4. Categories combined to form five equally weighted sections.

Combined categories	No of patients (%)
Side-effects of treatment/how will I feel	77%
Explanation of illness/prognosis/genetic risks	82%
Follow-up arrangements	94%
Treatment and care during radiation	96%
Overall satisfaction	95%

In our population, both State and Trait mean anxiety scores were significantly lower following radiation therapy.

All patients (100%) were satisfied with weekly radiation reviews during which a multidisciplinary team reviews patient's progress on treatment and side effects. A "scrums" is held where the entire team reviews the information and the most appropriate team members are assigned to meet the patient. Patients thought it was the key to success as they were able to discuss their symptoms and concerns elaborately with the staff. Patients used to wait for their review day with their list of questions, and, bring family members as it was another chance to discuss issues with oncology team after their new patient appointment. Patients considered weekly review held by multidisciplinary team to be a vital component in their radiation treatment.

Table- 5. Satisfaction scores according to information needs (personality type).

Mean ISQ score	Involved in decision	Prefer doctor to make decision	Prefer family to make decision	Prefer only positive information
0-4 very poor	02	00	00	01
5-9 poor	04	01	01	01
10-14 fair	53	00	00	00
15-19 good	26	02	00	00
20-24 excellent	09	00	00	00

Patients felt helped if the radiotherapist warned them of the side effects and if they were able to grasp and retain the information. They appreciated being forewarned and praised their doctors for knowing just what would help them. No one complained that his or her doctor warned him of a side effect which did not materialize. More likely, predictions which were not borne out are quickly forgotten and forgiven. They did not understand that a treatment that made them feel worse could actually have been beneficial: that their physical distress was related to effective dosage levels. Those who had been given no warning of side effects were disappointed and angry, making it difficult for them to question their doctors or to accept their doctors' belated explanations. Patients were asked to write additional comments. These comments were subsequently added into five weighted sections for example genetic risk was merged with explanation of illness & prognosis to form a section and logistical issues were merged with follow-up arrangements based on 80% of comments received. An additional question was also included in STAI to give patients the opportunity to provide a score for overall performance as shown in Table- 4.

The correlation of STAI scores before and after radiation was statistically significant. In our patient population both State and Trait mean anxiety scores were significantly lower following radiation therapy ($p<0.001$). The results of the two-sample t-test were significantly lower in post radiation period (State trait $r = 0.521$, Anxiety trait $r =0.701$) There was a consistent reduction in anxiety scores following radiotherapy in patients who want to be involved in the decision-making (type 1 personality) and those who want limited information and would prefer the doctor to make the decisions (type 3 personality). Although there are only twopatients who wanted positive information (type 2 personality), they appeared to have an increase in their mean anxiety scores following radiotherapy. In our study we found that patients wanting only positive information had higher anxiety scores and lower satisfaction scores (Table- 5). However we have very small numbers which cannot give any confirmatory results to deduce a statement. In future we need larger trials designed to further investigate the relationship between personality type based on information preference and satisfaction plus anxiety levels.

Discussion

While information disclosure statement actually refers to a submission of relevant information to patent prosecution system and, the, same analogy is being applied to any system where someone needs information to understand the situation better.(4) Similarly proper communication plays a vital role in channeling information to the receiver. It helps in coordinating, controlling and issuing instructions which usually brings improvement in the outcome whatever it may be. In, medicine it is imperative that we create an atmosphere of trust and confidence. Often patients feel perceptual, emotional or there is a cultural barrier and this makes them withdraw.(5) Despite present efforts to improve cancer patient education, recent studies reported between 10 and 28% of patients are not satisfied with the information they receive from their care giver.(6) Charles D. Spielberger rightly said that from the physician's perspective it is not always easy to tailor information to individual patient needs. A patient wants as much information as possible; satisfaction with the information provided may be more relevant for their quality of life, than, mere quantity of information given. If health care professionals can provide adequate information to the patient, it definitely has been shown to reduce anxiety and improve patient compliance.(7) State and trait anxieties are analogous in certain respects to kinetic and potential energy. S-Anxiety, like kinetic energy, refers to a palpable reaction or process taking place at a given time and level of intensity. T-Anxiety, like potential energy, refers to individual differences in reactions. Potential energy refers to differences in the amount of kinetic energy associated with a particular physical object, which may be released if triggered by an appropriate force. Trait Anxiety implies differences between people in the disposition to respond to stressful situations with varying amounts of S-Anxiety. But whether or not people who differ in T-Anxiety will show corresponding differences in S-Anxiety depends on the extent to which each of them perceives a specific situation as psychologically dangerous or threatening, and this is greatly influenced by each individual's past experience.(8)

Dr Berg et al published their study which evaluated preoperative information for ICU patients to reduce anxiety during and after the stay: randomized trial NCT 00151554. This study investigated the potential benefits of a specifically designed ICU-related information program for patients who undergo elective cardiac, abdominal or thoracic surgery and are scheduled for ICU stay. The trial is designed as a prospective randomized controlled trial including an intervention and a control group. The control group receives the standard preparation currently conducted by surgeons and anesthetists. The intervention group additionally receives a standardized information program with specific procedural, sensory and coping information about the ICU. They found that a proper information program would inform the patient about the aims, prospects and the specific elements of the scheduled stay. Thus, the patient learns that he/she is about to undergo a time-limited episode and that all is done in the best of his/her interest.(9) This information together with learning, how to best communicate and specific needs gives the patient back a sense of control in this difficult communicative situation. A number of other surgical studies indicate that patients profit from proper information with regard to various outcomes such as anxiety, pain and length of stay.(10) The same is true for any field of medicine. Even in oncology there is enough data showing that increasing information can reduce anxiety and improve satisfaction with system.(11) It is a known fact that tailoring information for individual patients while keeping their mental, social and spiritual needs under consideration is an extremely complicated process.(12) There is a suggestion that patients react differently with regard to anxiety, depression and satisfaction depending on their information needs/personality type. Thomas et al. found that following a diagnosis of cancer, patients who wanted all available information had significantly higher levels of anxiety than those who preferred to let the doctor decide. In this study, both groups of patients who wanted all available and limited information showed a reduction in anxiety scores following radiotherapy.(13) In Zissiadis et al study done on similar kind of population in Australia as ours found that in their patient pool both State and Trait mean anxiety scores were significantly lower following radiation therapy. There was a consistent reduction in anxiety scores following radiotherapy in patients who want to be involved in the decision-making (type 1 personality) and those who want limited information and would prefer the doctor to make the decisions (type 3 personality). Although there are few patients who wanted positive information only (type 2 personality), they appeared to have an increase in their mean anxiety scores following radiotherapy. Following their study they developed new information booklets addressing lifestyle and practical issues, which were not being adequately addressed as shown in the study.(14)

Patients who have received less information about radiation have the feeling of pessimism and biased beliefs. Patients feel unprepared and most of their personal, social, and cultural needs are unmet.(15) Johnson et al in their study found that descriptive information about radiation decreased the disruption to patient's lives and their treatment schedule.(16) Audiovisual education programmes have more impact on patients and their families. McPherson et al systematically reviewed randomized controlled trials that have evaluated methods of information given to cancer patients and their families. From this process, 10 studies were identified. Interventions ranged from written information to audiotapes, audiovisual aids and interactive media. Individually tailored methods such as patient care records and patient educational programmes were also reviewed. The evidence indicated that these interventions had positive effects on a number of patient outcomes, such as knowledge and recall, symptom management, satisfaction, preferences, health care utilization and affective states. This was above and beyond the usual care provision. In the majority of studies the interventions had no effect on psychological indices, however, furthermore, the review highlighted that certain methods should be based on individual preferences for information rather than uniformly administered.(17) Some researchers feel continual assessment of information needs during radiation treatment and post treatment is beneficial.(18) Written information pamphlets have unique advantage as it is a record which patient and family can access anytime at their convenience. The document should be simple, containing no acronyms and targeting core issues.(19) Crosson et al recommended that verbal information should be reinforced by pamphlets, cards, demonstration and group discussion. They formulated a guideline targeting few important areas where information usually is required. Most of the times patients have misconceptions relating to the nature of radiotherapy, description of the radiation room, administration of radiation (procedural, sensory and behavioral), expected side effects and other ways to treat the same disease.(20) There are also unique concerns which need to be addressed, necessitating, individualassessment on regular basis.(21) Despite the caveats and assumption in the design of our and other available tools in the literature, we found that it should be a very simple, practical tool so that it can identify any deficit in our system. In our setting we learned that providing adequate and relevant information is a challenge. Every patient despite their education level needs reinforcement from time to time. Furthermore, all these factors have been fed back to the staff within the unit so that they can clarify future verbal consultations. We are in the process of introducing weekly distress score pilot program for patients who are undergoing radiation to evaluate their psychological needs which are mostly ignored while we deal with cancer treatment which takes precedence. Now it is a known fact that increasing information and individualizing information can reduce anxiety and improve satisfaction with the health system which eventually will improve outcome. Nowadays in addition to handling complex cancer treatments, oncology teams should pay attention to other key factors which will decrease the threatening experience faced by our patients and their loved ones.(22)

Conclusion

The importance of giving information to patients prior to diagnostic and therapeutic procedures is a well established fact. Research has established many barriers for proper communication. The Oncologist should be aware that most patients will not ask questions on their first visit as they are overwhelmed with their dreadful diagnosis and, consequently, they should make special provisions for questioning. The initial meeting should be unhurried, and since there is a risk that some information imparted may not be grasped or remembered, there should be planned opportunities for repetitions. Several repetitions and subsequent visits may be needed for a patient to hear what is said, respond to it, and retain this information in their mind.

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