Patient perspectives on the impact of receiving radioactive iodine: Implications for practice

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Abstract

The purpose of this study was to identify the needs of patients undergoing treatment with radioactive iodine (II31). This descriptive study used a standardized survey which was completed by 190 patients selected from eight programs across Canada that deliver II31. One hundred were treated as inpatients and 90 were treated as outpatients. Data from this study indicate there is a variation in patients' perceptions about how precautions are to be implemented during II31 treatment. Patients expressed a desire for more information regarding many aspects of the treatment experience and the medium through which information is provided. There are also implications for support of patients in terms of dealing with psychosocial issues which emerge when living with thyroid disease.

Radioactive iodine (I131) has a long-established role in the treatment of hyperthyroidism and thyroid carcinoma (Atomic Energy Control Board, 1993). Approximately 13,000 patients are treated with I131 for thyrotoxicosis or thyroid cancer in Canada each year (D. Dreidger, personal communication, March 4, 1998). When people are treated with radioactive iodine, they become a temporary source of ionizing radiation to other persons with whom they come in close proximity. Thus, certain measures have been established to protect those who routinely come in contact with treated patients (Barrington, Kettle, Doherty et al., 1996; Barrington, Kettle, & Thomson, 1996; Culver & Cworkin, 1992).

Traditionally, radioactivity levels have been used to determine if a patient requires hospitalization and isolation procedures. It has been standard practice for many years to admit patients, simply to quarantine them from others until the level of radiation decay is at a predetermined level (i.e., 1GBq for I131 therapy). Once patients are discharged, and for patients who are treated on an outpatient basis, specific precautions are implemented at home to further isolate themselves from others (Atomic Energy Control Board, 1993).

The set limits and the assumptions which underlie the usage of standard limits have come under question recently (Barrington, Kettle, O'Doherty, et al., 1996; Barrington, Kettle, & Thomson, 1996; Carey, Kumpuris, & Wrobel, 1995; Culver & Cworkin, 1992). Questions are being raised about the best approach to care for these patients, especially in light of the growing body of literature on the real hazards to the public and the context of current hospital bed utilization issues. Advocates are calling for guidelines that are not guided by worst-case scenarios and that are sensitive to patient needs, rights, and responsibilities.

In 1997, the Canadian Atomic Energy Control Board (AECB) Advisory Committee on Radiological Protection and the AECB Group of Medical Advisors (GMA) formed a joint working group to develop new guidelines for the management of radionuclide therapies. The guidelines were to include principles for managing the potential exposure to the family, clinical support staff, and the public from patients who have received therapeutic doses of radionuclides. It is anticipated that these guidelines will serve as a comprehensive and uniform guidance for all Canadian medical institutions performing new and established radionuclide therapies.

An important aspect of developing new guidelines is understanding the current experiences of patients receiving radionuclide therapies. In addition, it is important to identify the potential impact, both positive and negative, on individuals and family members, if changes in guidelines were to occur. To date, little has been written about the patient perspective on receiving radionuclide therapy, the experience of the isolation, or the impact this therapy has on otherwise healthy individuals and their families. The current literature on radionuclide therapies is heavily based on the health care professionals' perspectives and provides little information regarding what patients identify as their needs and concerns.

Hence, this project was undertaken to gain an understanding of patients' and family members' perspectives about receiving radionuclide therapy, specifically radioactive iodine. This article reports on the patient's perspectives in relation to two areas of the study: their information needs and the experience of protective measures.

Methods

Sample

Patients who had received radioactive iodine (I131) were selected as the sample population for this cross-sectional descriptive study. The inclusion criteria included being older than 12 years of age with a malignant or nonmalignant diagnosis, and treated with any dose of I131. This group was selected because of the large number of patients treated with I131, and because the precautions taken during I131 therapy have been used as a model to guide the approach to other radiopharmaceuticals.

Accrual

A standardized survey was used to gather data in this study. A total of 700 survey packages were distributed to physicians in eight clinics or sites across Canada where radioactive iodine therapy was delivered. The location sites included Newfoundland, Nova Scotia, Ontario (two sites), Quebec (two sites), Manitoba, and British Columbia. Ethics approval for the project was obtained from all sites. Upon receipt of the surveys, each physician identified, from his or her caseload, 35 patients with a malignant diagnosis and 35 patients with a nonmalignant disease who had received I131 treatment within the past two years.

Survey packages were then mailed by the respective clinics to the selected patients. The packages contained a letter of explanation, a copy of the survey, and a pre-stamped return envelope. The letter of explanation indicated that consent would be implied if the patient returned the survey completed. The patient completed the survey at home and returned it to the researcher's office. Thus, the researcher was not aware of the patients' names and the physicians were not aware who had participated in the study. Given this arrangement, no follow-up reminders were sent to patients.

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Survey instrument

The survey instrument used in this work was developed for the purposes of this study. The items were crafted following indepth interviews with 21 patients who had undergone treatment with I131. The format of the survey was based on a survey format used successfully with prostate cancer patients (Gray et al., 1997) and ovarian cancer patients (Fitch, Gray, DePetrillo, Franssen, & Howell, 1999).

The survey was designed to elicit patients' perspectives regarding the following topic areas: diagnostic process, treatment, precautions used, problems experienced, assistance received for problems, importance and satisfaction with information, satisfaction with communication with health care professionals, support, and impact on lifestyle. The survey items were pre-coded with response options generated from the indepth interviews. The majority presented a list of options and the respondents marked those which applied to them. Five-point Likert-type scales were

Characteristics	Inpatients (n=100)	Outpatients (n=90)	Total (n=190)
Age			
(average in years)	50.9	45.5	
(range in years)	14–84	12–77	
Gender			
Male	26%	25.6%	25.4%
Female	66%	72.2%	69.4%
Culture			
Caucasian	85%	84.4%	85.0%
Other	14%	14.4%	14.0%
Marital status			
Married/Common law	71%	63.3%	66.8%
Never married/separated/			
divorced/ widowed	29%	36.7%	32.6%
Highest education level			
No formal	0%	3.3%	1.6%
Primary	9%	10%	9.3%
Secondary	35%	45.6%	40.4%
College/University	54%	40.0%	47.1%
Work			
Caring for family	21%	20%	20.2%
Work (paid or volunteer)	46%	51.1%	47.7%
Looking for work	0%	5.6%	2.6%
Retired	24%	18.9%	21.2%
Going to school	10%	7.8%	8.8%
Unable to do my			
normal activity	12%	8.9%	10.4%
Other	1%	1.1%	1.0%
Income level			
Less than \$10,000	2%	11.1%	6.7%
10,000 - 29,999	22%	16.7%	19.7%
30,000 - 59,999	34%	27.7%	31.1%
60,000 – 99,999	17%	9.3%	18.1%
100,000 or more	11%	4.4%	7.8%
Don't know	8%	11.1%	9.3%
Community population			
Less than 5,000	25%	31.1%	28%
5,000–49,999	21%	21.1%	20.7%
50,000–249,999	15%	5.6%	11.4%
250,000–999,999	15%	16.7%	15.5%
1 million or more	17%	17.8%	17.1%

used to assess the importance of information and the impact of the diagnosis and treatment on lifestyle. Opportunities to write additional responses were offered throughout the document. This paper reports the data regarding precautions and information needs.

Data analysis

Data analysis for the survey was descriptive. Data from individuals who had been treated as inpatients and outpatients were analyzed separately because the treatment protocols differ for these patient groups. Item means, medians, and frequencies were calculated. Open-ended questions were reviewed and subjected to a standard content analysis. Examples of the written comments are reported to illustrate specific points.

Results

Demographic characteristics

A total of 190 patients returned the survey (response rate of 27%). One hundred had been treated as inpatients and 90 were treated as outpatients. Table One presents the demographic information from the patients in each group.

Overall, the patients had an average age of 48.7 years (range 12 to 84). Almost three-quarters (69.4%) of the respondents were female and 85% were Caucasian. Two-thirds (66.8%) were married or living with a partner. The majority (87.5%) had completed high school and almost half (47.1%) had also completed community college or university. Approximately one-third (31.1%) had an income between \$30,000 and \$59,999. Almost a third (28%) lived in small communities of less than 5,000 and 20.7% lived in communities with populations between 5,000 and 49,999. Responses were received from each of the six provinces where surveys were distributed.

The majority of both inpatient (84%) and outpatient (80%) respondents were living with an adult partner at the time they received their radioactive iodine therapy. Many (43% and 39%) were also living with children, of whom half were under the age of 12 years.

Both inpatient and outpatient groups had a mix of patients with malignant and nonmalignant disease and a cross-section of

Table Two: Diagnosis/treatment characteristics				
	Percentag	Percentage of patients		
Characteristics	Inpatients (n=100)	Outpatients (n=90)		
Diagnosis				
Malignant	64.0	4.44		
Nonmalignant	12.0	80.0		
Other	20.0	10.0		
Time since diagnosis				
0–1 year	48.0	44.4		
2–3 years	30.0	35.6		
4–5 years	8.0	12.2		
>5 years	12.0	5.56		
Treatment received				
Partial thyroidectomy	18.0	2.22		
Total thyroidectomy	85.0	7.78		
Radioactive iodine	100.0	100.0		
External radiation	11.0	1.11		
Medication	65.0	67.8		
Currently on medication	92.0	60.0		
Number of radioactive				
iodine treatments				
One	57.0	80.08		
Two	34.0	14.4		
Three or more	9.0	5.56		

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individuals who had been diagnosed more than a year prior to the survey and treated with I131 on more than one occasion. Table Two displays diagnosis and treatment information for the respondents.

Access to information

The majority of both inpatient (78%) and outpatient (86%) respondents indicated they had had someone with whom to talk about the diagnosis and treatment during the six weeks following their diagnosis. Inpatient respondents listed a variety of health care professionals with whom they could talk, including family doctor (55%), general surgeon (52%), endocrinologist (25%), oncologists (21%), nuclear medicine physician (19%), and nurse (11%). The outpatient respondents indicated they could talk with the family doctor (74%), endocrinologist (57%), and nuclear medicine physician (29%). The majority of respondents in both groups indicated they had received clear explanations about the treatment (84% and 79%) and anticipated side effects (74% and 70%).

The majority of respondents in each group rated information about their medical condition, tests and procedures, treatment choices, and side effects of treatments as very important (see Table Three). Topics such as preparing one's home for the time after treatment, how to relieve physical discomfort, preparing for hospitalization, diet and nutrition, and emotional side effects were also considered very important by more than two-thirds of the respondents. However, across all topics, no more than 72% of the respondents indicated feeling satisfied with the information they had received. The topics for which the lowest proportions of respondents indicated satisfaction were how to arrange to speak with another patient in the same situation, availability of counselling services, emotional effects, and diet and nutrition.

Relatively few respondents reported that they received information about and/or help from formal support organizations. The inpatient group reported receiving help most frequently from the Thyroid Foundation of Canada (8%) and the Canadian Cancer Society (4%) while the outpatient group received help from the Thyroid Foundation of Canada (8%). Respondents who received help from these agencies shared the following comments:

My greatest help has come from [the peer support volunteer] from Cancer Connection - a wonderful telephone service with which my daughter put me in touch.

Any information would have been helpful, even knowing that there was a Thyroid Foundation or that what I was feeling was normal. There should be an automatic hand-out from the Thyroid Foundation for people who are diagnosed with thyroidism.

Precautions

Patients who received their treatment on an inpatient basis were asked what precautions were put in place during that time. Table Four presents their responses. The most frequently identified precautions were that the radioactive iodine was in a special container (98%), the patient drank lots of fluids (94%), the patient flushed the toilet twice (93%), and others kept their distance from the patient (91%).

All but one of the inpatients were isolated during their hospitalization for treatment. Approximately three-quarters (73%) were isolated for two to three days, while 16% were isolated for longer than three days. Comments from the patients who experienced difficulties with the isolation reflected the following:

The part of the hospital stay that made things so difficult was the isolation in the room. The nurses, for the most part, were inexperienced and obviously hesitant to be exposed to me. I was very unwell the first night of my treatment (nausea and vomiting) and felt very alone...I wish I had received some extra emotional support, if only talking to me through the intercom.

Should be a TV in room that works and is turned on. I was upset because they would not turn TV on or take my money. Appreciated phone...was not given any information ahead of time that I would be in isolation. Shower would have been nice.

I have had three treatments. My biggest complaint is no shower and cold meals. I recommend: 1) have a shower available, 2)

Table Three: Information patients reported as important and satisfaction with the information received				
	Inpatients		Outpatients	
Торіс	Percentage indicating the topic was important*	Percentage satisfied with the information received**	Percentage indicating the topic was important*	Percentage satisfied with the information received**
Medical condition	92.0	65.0	92.2	68.9
Planning for tests and procedures	87.0	72.0	83.3	71.1
Treatment choices available	0.88	62.0	91.1	72.2
Possible side effects of treatment	0.88	55.0	88.9	62.2
Possible emotional effects	67.0	43.0	73.3	53.3
What to do to relieve physical discomi	fort 69.0	60.0	70.0	53.3
Diet and nutrition	63.0	45.0	71.1	44.4
Counselling services available	42.0	30.0	44.4	30.0
How to arrange to speak with another person with the same condition	on 49.0	28.0	41.1	33.3
Preparing for hospitalization	67.0	67.0	31.1	34.4
Preparing your home after treatment	71.0	61.0	54.4	53.3

^{*} Respondents indicating 4 or 5 on a scale where 1 = not at all and 5 = extremely important.

^{**} Respondents indicating YES on a dichotomous item.

bigger room to do exercises, etc., 3) have a real TV - 20" with some tapes and VCR, 4) let the nurses know they won't die by opening the door and talking to you for a few minutes, 5) kitchen help would leave food outside door. I would wait sometimes 30 to 45 minutes for it...treatment and physical health was fine. Being treated like BLACK DEATH got on my nerves...

Comments written by patients also reflected the desire for more information about precautions. For example, "[it would be helpful to have] a printed copy of instructions when receiving the radioactive iodine in the hospital rather than just an oral explanation of all the DOs and DON'Ts."

Patients were asked what made the interval in hospital easier. The following suggestions were made: television and telephone in the room (80%), window in the room (70%), nurse (39%), physician (27%), technician (22%), reading/school work (22%), and visitors (19%).

All respondents were asked what precautions were put in place in the home environment following the administration of I131 (see Table Five). For the inpatients who had been discharged home, the precautions identified by the largest number of patients included washing hands thoroughly (91%), drinking lots of fluids (86%), and flushing the toilet twice (84%). For the outpatients, the most frequently identified precautions included washing hands thoroughly (82%), flushing the toilet twice (79%), and avoiding contact with children and women who are pregnant (71%). Overall, more respondents in the inpatient group indicated precautions were in place at home than did the outpatient group.

When asked which precautions were difficult for the patients, the inpatients identified: experiencing a great deal of difficulty with being unable to do the things they normally did (42%), being off the thyroid medication prior to treatment (41%), being unable to get too close to children or family (39%), being isolated or staying alone (27%), and being unable to have visitors (27%). The outpatient respondents indicated they had difficulty with being unable to get too close to family members or children (29%) and being unable to do the things they normally did (24%).

Respondents indicated they did have concerns about the I131 once they were at home. Both inpatients and outpatients identified concerns or worries about others receiving a dose of radiation from them (53% and 42%), what the radiation would

Table Four: Precautions used during

inpatient radioactive iodine treatment				
Precaution	Percentage of inpatients (n=100)			
Radioactive iodine was in a special container	98			
Patient drank lots of fluids	94			
Flushed toilet twice	93			
Others kept their distance	91			
Patient washed hands thoroughly	88			
Laundry kept in room	85			
Dishes left in room	82			
Technician wore gloves	79			
Radioactivity measured daily	77			
Not able to have visitors	61			
Patient sucked on candy/lemons	57			
Patient showered frequently	28			
Visitors stayed short time	25			

do to the rest of their bodies (52% and 62%), how to know when the radiation is gone (50% and 43%), and how to remain isolated from others (35% and 20%). Additionally, they thought their family members were also concerned about whether the treatment would work (57% and 58%), how to know when the radiation was gone (47% and 40%), and the possibility of being contaminated (37% and 29%). The following comment reflects the concerns patients wrote about:

I keep wondering, if it's so dangerous, how can it be safe to give to us. It doesn't kill the ones who receive it, so it makes me wonder if it is as bad as some people think. I find that my father gets worried. He wonders how it will affect the rest of my body, when it is strong enough to kill the cancer...

The individuals who received their treatment as inpatients were specifically asked if they would consider receiving radioactive iodine therapy on an outpatient basis should they require another treatment. More than half (58%) indicated they would not consider having future radioactive iodine treatments on an outpatient basis, while 22% were uncertain if they would. The concerns they identified included: wondering whether other people would receive a dose of radiation from them (81%); wondering how the patient could know that the radiation was gone (73%); wondering if the radiation would contaminate the house (71%); and feeling that they would need more information to receive the treatment as an outpatient (59%).

Discussion

This study was conducted to gather perspectives from patients about receiving I131. It was thought to be important to incorporate patient perspectives in the development of new principles for managing the delivery of this treatment modality.

A limitation of this work is the small sample size. The distribution of the surveys occurred according to the original plan and surveys were returned from all locations where they were distributed.

Table Five: Precautions taken at home following radioactive iodine treatment

	Percentage of patients		
Precaution	Received treatment as an inpatient (n=100)	Received treatment as an outpatient (n=90)	
Washed hands thoroughly	91.0	82.2	
Drank lots of fluid	86.0	54.4	
Flushed toilet twice	84.0	78.9	
Avoided contact with children/pregnant women Slept alone Avoided kissing/hugging Kept distance from family Showered frequently Kept distance from others	77.0 72.0 70.0 59.0 57.0 50.0	71.1 54.4 57.8 45.6 36.7 51.1	
Used own utensils or plastic utensils	50.0	51.1	
Stayed by self in separate room	44.0	23.3	
Washed clothes/linen separately	43.0	26.7	
Stopped breast feeding	4.0	1.1	
Other	6.0	7.7	
Didn't know I needed precaution	0	3.3	

Although the response rate actually exceeds those of general mailings without reminder notices, generalizability of the findings may be somewhat limited.

Another limitation, as is the case with all mailed surveys, is that those who returned the completed forms are likely those individuals with an interest in the topic or individuals who have the ability to read and articulate responses to a document such as the survey instrument. Thus, the findings may under-represent the views of individuals who are less educated and individuals who lack facility with English or French. In addition, this sample is not reflective of the wide cultural and ethnic community within Canada.

Despite the limitations, this is the first Canada-wide survey regarding the perspectives of individuals who have received radioactive iodine treatment. Responses were received from all provinces in which distribution occurred and from a good cross-section of community sizes. The results provide interesting insights and offer implications for future investigations.

The ratio of female to male respondents approximates the incidence by gender of thyroid disease (Baker & Feldman, 1993). The treatment information is in keeping with the nature of the diseases and the normal course of treatment. Individuals with malignant disease are more likely to be treated on an inpatient basis, to undergo surgery, and to receive higher doses of radioactive iodine.

Information issues

Many respondents in both the inpatient and the outpatient group indicated they felt informed about their disease and side effects and felt they had someone with whom they could talk about these matters. However, there were groups of respondents who did not have the explanations they felt they needed and did not have individuals with whom to talk. The challenge for health care providers is to be able to identify this group of patients who need more information and find approaches to meet their needs.

Clearly, information was perceived as important to individuals treated on either an inpatient or an outpatient basis. Respondents were relatively satisfied about the information they received concerning their medical condition, tests, procedures, treatment choices, and side effects of treatment. However, they were less satisfied with the information they received concerning emotional reactions, supports available for them, and the steps they can take to cope with their situation. These observations have implications for patient education and the type of health care professionals with which the patient comes in contact. Nurses, nutritionists, and social workers may need to be part of the treatment teams for this patient population. Family physicians may also need to have information about radioactive therapy readily available in their offices, so that patient and family fears can be reduced as early as possible.

Also noted in the study is the need for the use of other media to provide information, in addition to talking with patients. The need to develop written information that can be provided to patients prior to receiving their treatment was reported as important to this patient population. This may help alleviate unnecessary concerns about the room size and precautions, and help the patients and their families prepare their homes prior to discharge.

More than half of the respondents indicated a need to talk to someone else about issues related to their disease. Although many had someone with whom they could talk and a few were able to see a professional counsellor, very few individuals had the opportunity to attend self-help groups or to access the services of the Thyroid Foundation of Canada or the Canadian Cancer Society. Both of these organizations provide services to patients, especially in terms of patient information. A challenge for those providing care to this population of patients is to ensure the patients and families are aware of the community services which are available to them and how those services can be accessed. The challenge for the agencies is to provide sensitive, culturally appropriate service.

Precautions

At first glance, it is somewhat surprising that precautions were not reported as used by 100% of the respondents. However, the proportion of respondents citing the precautions they used could reflect a number of factors: what the patients observed at the time, what the patient was told to do, what the patient remembers doing, the policies in use at a particular institution, and the environmental reality. Also, there are variations in practices between inpatient and outpatient protocols. This variation is possibly related to the different dosage levels for these two groups of patients, and the amount of thyroid tissue the patient possessed. However, one would expect to see similar practices and instructions about precautions within groups.

Overall, a large proportion of the inpatient group reported similar approaches to precautions while in hospital. Variation emerged most often around the issues of showering and visitors. Currently, there are hospitals that still do not have showers in all patient rooms, and practices vary from institution to institution about allowing visitors to see patients who are in isolation for I131 therapy. This latter observation points to the need for evidence-based guidelines regarding visitation for patients in this situation.

Overall, the patients who were informed and expected to be in isolation did not find it particularly difficult. Of note are the patient perspectives about what made the isolation easier. These aspects were primarily social in nature: contact with family, friends, and professionals; having access to a telephone or television, and windows (with a view) in the room. Clearly there are implications in these suggestions for institutions providing inpatient I131 therapy. Key strategies include ensuring that patients have the correct information about isolation and that they receive it in a timely and sensitive manner prior to admission. Also, improvements should be made to make the room more comfortable and feel less isolated.

Overall, the aspects surrounding the precautions that patients found difficult concerned not being able to do what they normally do, being off their usual thyroid medications, and not being able to get close to family members. These types of difficulties reflect interference with normal daily activities and are the types of difficulties frequently cited by patients who are undergoing other types of treatment. Disruption in usual life activities often evokes frustration and distress, with the potential for distress increasing the longer the treatment interval lasts. Health care providers need to be aware of these issues and help patients plan for coping with them prior to treatment. As well, during the treatment interval, providers need to assess the patient's level of distress and intervene as required.

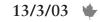
The concerns patients expressed about the radiation after they were home clearly have implications for patient education. Most of the issues related to worry that others would receive a dose of radiation, wondering how one would know that the radiation was gone, and wondering what the radiation would do to the rest of the body. Interpretation of precautions could also play a role here. Precautions such as "do not get too close to family members" and "keep your distance from others" ought to be explained using concrete examples of what is meant (i.e., an arm's length away). Providing this information in written form will also assist patients and families in preparing the home environment prior to going for treatment.

Conclusion

This Canada-wide survey provided perspectives from patients about their experiences regarding radioactive iodine therapy. Data indicated there is variation in patient perceptions about how precautions are to be implemented. Patients expressed a desire for more information regarding many aspects of the treatment experience. Additionally, there are implications for support of patients in terms of dealing with psychosocial issues which emerge when living with thyroid disease.

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