

An evaluation study of the perceptions of oncology staff on the problems and solutions in care of children undergoing radiotherapy.

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Abstract

PURPOSE: To establish, by means of an analytical descriptive study, what problems are encountered by oncology staff when dealing with children undergoing radiotherapy, in order to assess their opinions on the appointment of a pediatric radiographer as one way of improving the quality of care for these category of patients.

METHOD: A survey questionnaire was used to obtain data pertaining to the experiences and opinions of staff in a busy oncology department at a large tertiary hospital in the Western Cape. The responses were analysed and evaluated to determine the scope of the problems and solutions suggested.

RESULTS: Fifty-two questionnaires were returned out of a total of 62, a response rate of 84%. The majority of respondents had encountered some children showing high apprehension on the machines at the beginning of their radiation therapy (98%), followed by planning (96%), clinics (93%), mould room (93%), with the least apprehension shown towards the end of their radiation therapy. The time when parents and radiographers leave the treatment room was reported to be a particularly anxious period for the child as 83% felt some children are not relaxed during the radiation treatment, which may impact on treatment accuracy. Encounters with fearful children had at times been experienced by 46% of the respondents while 58% had encounters with depressed parents. The study also established that at times these problems require sedation being given to the child; 67% of the respondents felt the current methods used to calm children in the department were not very effective compared to 33% who felt they were quite effective ($p = 0.001$). A high majority (83%) acknowledged mock treatment set-ups after the conclusion of radiation planning would be of benefit. Seventy-three percent of respondents recommended that a post of pediatric radiographer should be created versus 23% that were against this idea.

CONCLUSION: For children undergoing radiotherapy and their parents, a pediatric radiographer may be one method to relieve anxiety and stress during this difficult time in their lives. Given that children visiting the oncology department are from different socio-cultural backgrounds and may vary in their developmental stage, no one solution can be deemed ultimate in dealing with this complex situation. Further efforts are needed to achieve workable solutions to this problem depending on the circumstances and situation.

Keywords: pediatric, radiographer/radiation therapist, treatment/patient set-up, motion control, treatment accuracy.

Introduction

Pimm *et al* [1] make worthwhile observations regarding the emotions exhibited by adult cancer patients on their first visit to a radiotherapy department and the subsequent treatment they are to receive. They note that this has led to advances being made over the years to address this issue with most radiotherapy departments providing written information about the treatment and what it will entail prior to the first visit. They emphasize that many departments employ specialist cancer care radiographers or nurses to provide extra support of a practical and emotional nature. Despite these measures, they point out that the needs of a young child with a diagnosis of cancer have until recently not been adequately addressed, nor indeed have the needs of parents of a child undergoing radiotherapy. The awesome aspect of the therapy machines [2], and the different stabilization devices may be quite intimidating and scary to the child [1]. These may make it quite difficult for the child to co-operate fully with the staff's instructions, a fact that may compound problems for radiographers in terms of patient set-up and accurate treatment delivery. To solve this problem most departments often use sedation to ensure adequate motion control [3] thereby

avoiding irradiation of normal tissues during a course of treatment [4]. The use of sedation or anaesthesia adds risk and expense to a procedure that does not require pain management [3] since the radiation treatments are not painful [3,5]. As noted by Bucholtz [6], this aggressive and intensive treatment for children and families experiencing a cancer diagnosis requires a maximum comfort approach. She mentions the need for psychological preparation for medical procedures and experiences that should involve communication about forthcoming events, so as to desensitize the child to the steps and equipment to be used in order to reduce anxiety and evoke the child's cooperation.

Thus considering these issues and the fact that radiation therapy can be a particularly stressful experience for children [6] this study covered various problems experienced by oncology staff when dealing with pediatric cancer patients and possible solutions, such as the need to appoint a pediatric radiographer, to address possible need for improved quality of care of children undergoing treatment.

Methods

A questionnaire comprising 21 closed and two

open-ended questions was used. Though closed-ended questions constrain the respondent to a limited number of choices, they allow ease of analysis as they are recorded by use of a numerical code in an abbreviated format [7]. On the other hand, open-ended questions give respondents an opportunity to express themselves fully in their own language [8]. Thus it was felt appropriate to place two open-ended questions at the end of the questionnaire. Permission was obtained to distribute the questionnaire to all consultants, registrars, radiographers, mould room radiation technologists, and all professional oncology nurses at a large tertiary hospital in the Western Cape. A questionnaire was chosen as the tool to gather the required information since it is cost-effective and efficient in studies where time is a constraint factor [9]. Simple language was used to minimize ambiguity or bias and to ensure ease of completion. Easy to follow instructions were used with logical flow through the topics of information required so that the respondents could complete the entire questionnaire [10].

The study aimed to solicit views from a wide spectrum of the diverse disciplines involved in the care and treatment of pediatric cancer patients visiting the oncology department. The survey

targeted all oncology staff who were thought to have the highest interaction with these patients. The questionnaire was distributed to

- 30 out of 33 radiographers; three were on leave,
- 10 out of 11 registrars, one was on leave,
- all nine consultants,
- all three mould room radiation technologists, and
- all 10 professional oncology nurses in the department.

The oncology department is extremely busy as staff have high work levels to achieve. It was therefore decided that the study should be conducted in three phases to cover the entire sample size selected in order to achieve a high response rate with minimum disruption to the workload of those participating. The first phase involved all the radiographers. The second phase included all the consultants and registrars, and the third phase covered all the professional oncology nurses in the department.

Some of the topics included in the questionnaire were:

- apprehension of children when in the oncology department,
- time when parents and radiographers leave the treatment room being an anxious period for the child,
- reduced treatment accuracy due to non-relaxation of children during radiation treatment,
- time wastage as a result of difficulties encountered in treating children during high workloads,
- difficulties encountered resulting in the possibility of administration of sedation to the child,
- staffs' encounters with depressed parents due to the series of visits they have to make to the treatment units,
- effectiveness of current methods used to calm children undergoing radiotherapy,
- respondents' view on some of the factors a pediatric radiographer may improve for the child and parents,
- respondents' view on what might help a child in radiotherapy,
- respondents' recommendations on the creation of a post of a pediatric radiographer.

A week was allowed for the completion and return

of the questionnaires. Results of the completed questionnaires were reviewed and analyzed to compare respondents' answers, comments, and the significance of the differences between sets of responses using the chi-square test by two computer software packages Statistica and EpiInfo version 6.04. Differences of 5% were considered significant.

Results

Out of the 62 questionnaires distributed, 52 were adequately completed and returned representing an overall response rate of 84%. Not all respondents answered every question. The remainder of the questionnaires were either not returned or were returned blank. Some reasons for these were:

- consultants who do not treat children could not answer the questions,
- registrars who had not yet undergone rotation through clinics that deal with children malignancies,
- oncology nurses who knew little about children in the department could not adequately answer the questions thus all 10 questionnaires from these potential participants were not included in the study.

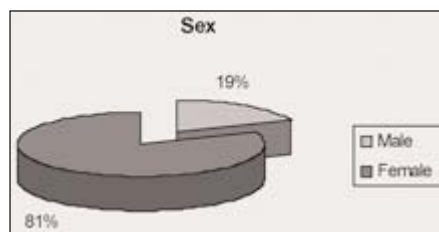


Figure 1. Respondents by sex (n=52).

The majority of the respondents were female making up 81% (n=42), with the remaining 19% (n=10) being male (Figure 1). The working experience of respondents in the department was 88% (n=46) for those exceeding two years and 12% (n=6) for those equaling or below two years

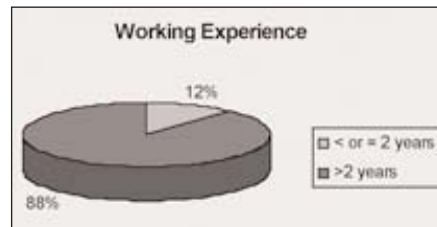


Figure 2. Respondents' years of experience (n=52).

(Figure 2). The highest questionnaire returns were from radiographers and mould room radiation technologists, namely a 100% response respectively. Registrars 80%, consultants 66.7%, and professional oncology nurses 50%. Sixty one percent (n=32) of the questionnaires returned had

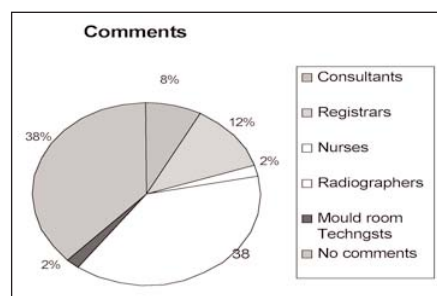


Figure 3. Percentage of questionnaires returned from the sample groups.

comments, with 38% (n=20) of these comments from radiographers (Figure 3). On the problems exhibited by children while in the oncology department, the majority of the respondents experienced some children who were particularly apprehensive when on the machines at the start of their radiation treatment (98%, n=44), in planning (96%, n=44), clinics (93%, n=28), mould room

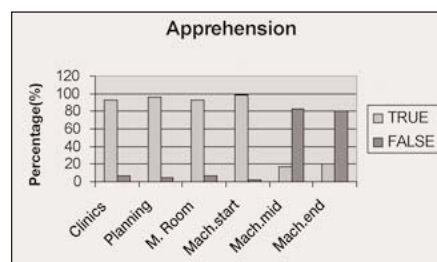


Figure 4a. Apprehension shown by children as reflected by staff responses - excluding the 'Not sure' and 'No response' group.

Table 1. Apprehension: The question stated: 'Some children are particularly apprehensive when they visit: Clinics, Planning, Mould room, Machines at start, machines in the middle, machines at end of their radiation treatment.'

n = 52 for each case

	True		False		Not sure		No Response	
	n	%	n	%	n	%	n	%
Clinics	28	93	2	7	20	38	2	4
Planning	44	96	2	4	4	8	2	4
Mouldroom	40	93	3	7	6	11	3	6
Mach/start	44	98	1	2	4	8	3	6
Mach/mid	6	17	30	83	13	25	3	6
Mach/end	8	20	32	80	10	19	2	4

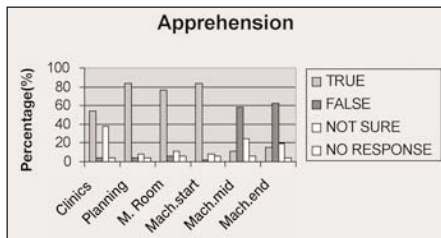


Figure 4b. Including the 'Not sure' and the 'No response' group (n=52).

(93%, n=40), with the least apprehension shown towards the end of their radiation treatment (Table 1 & Figure 4a). When those who were not sure and non-respondents were included in the result analysis, no significant differences emerged with the same high trend still being observed notably in machines/start (84%), planning (84%), and mould room (77%) (Table 1 & Figure 4b).

The experiences of oncology staff are summarized in Table 2 and Figure 5. The majority of respondents (83%, n=43) stated that the time when radiographers and parents leave the treatment room was a particularly anxious one for the child who is left alone in strange surroundings. Eighty three percent (n=43) felt some of the children undergoing therapy were not relaxed during the radiation treatment which may lead to reduced treatment accuracy. A large minority (42%, n=22) stated the frequent difficulties encountered in treating children resulted in time wastage during high workloads, as opposed to 52% (n= 27), who felt it only occurred sometimes.

Fifty eight percent (n=30) of respondents had at times encounters with parents who were depressed by the series of visits they had to make to the treatment units while seventeen percent

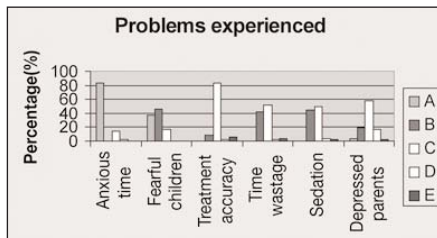


Figure 5. Problems experienced by staff when dealing with children in oncology as reflected by their responses (n=52).

(n=9) did not have these experiences with parents. However, 46% (n=24) reported encounters sometimes with fearful children undergoing radiotherapy procedures as compared to 37% (n=19) who felt the encounters were more often. Only forty four percent (n= 23) singled out this problems as frequently resulting in the administration of sedation to the child, with fifty percent (n=26) responding that it was done only sometimes (Table 2 & Figure 5). Comparison of these results with analysis excluding the no response group showed no significant differences in the trends of the respondents.

As regards the frequency of occurrence of these problems, 60% (n=29) felt they were

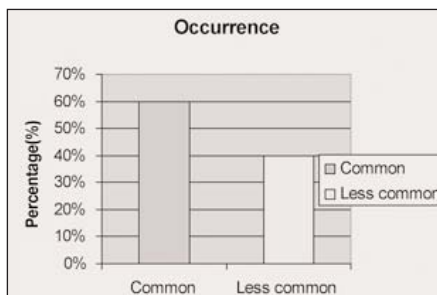


Figure 6. Frequency of occurrence of difficult children undergoing radiotherapy as reflected by staff responses (n=48).

Problem	Response	n	%
Anxious Time:	A. True	43	83
	B. False	0	0
	C. Not sure	8	15
	D. No response	1	2
Fearful Children:	A. Often	19	37
	B. Sometimes	24	46
	C. Seldom	9	17
	D. Never	0	0
	E. No response	0	0
Treatment Accuracy:	A. All	0	0
	B. Most of them	5	9
	C. Some	43	83
	D. None	1	2
	E. No response	3	6
Time Wastage:	A. Always	0	0
	B. Frequently	22	42
	C. Sometimes	27	52
	D. Never	1	2
	E. No response	2	4
Sedation:	A. Always	0	0
	B. Frequently	23	44
	C. Sometimes	26	50
	D. Never	2	4
	E. No response	1	2
Depressed Parents:	A. All	2	4
	B. Most of them	10	19
	C. Some	30	58
	D. None	9	17
	E. No response	1	2

common, 40% (n=19) stated they occurred less frequently (Figure 6). The four who did not respond to this question were excluded in the analysis. The difference between the two groups is statistically significant with a p value of 0.04. In addition, a large minority (47%) of staff have experienced children between the ages of 2-4 years as being the most problematic during radiotherapy procedures, with 36% not being able to remember any particular age group.

On the effectiveness of the current methods used in the department to calm children undergoing radiotherapy, only 33% (n=17) of the respondents felt they were quite effective; the

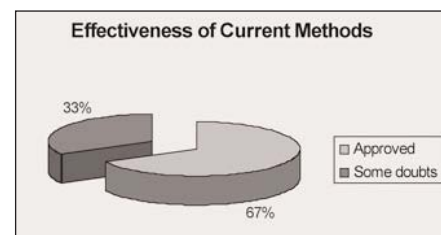


Figure 7. Percentage of staff responses on the effectiveness of current methods used to calm children undergoing.

majority (67%, n=35) felt they were moderately or slightly effective. The difference between those who expressed outright approval (quite effective) versus those who showed some doubts (either slightly or moderately effective) is statistically significant with a p value of 0.001 (Figure 7).

When asked their opinion on what benefits of appointing a paediatric radiographer would be to improve the problems the child and his/parents experienced, 40% (n=21) stated this to be information. Other benefits listed were support (37%, n= 19), make experience in oncology better (37%, n= 19), and reduction of anxiety (27%, n= 14). The respondents were asked to score more than one recommendation on a number of solutions suggested and a large number (83%) indicated 'mock treatment set-ups after therapy planning' as one solution to help a child in radiotherapy. 'Sedation' had the lowest support (46%). Despite these varying opinions an

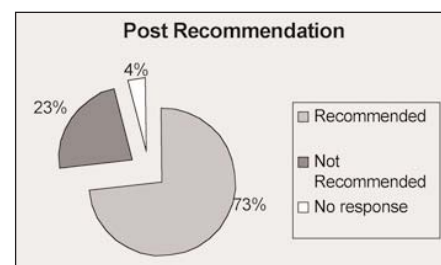


Figure 8. Responses regarding creation of post for paediatric radiographer (n=52).

overwhelming majority (73%, n=38) were still in favor of the creation of a post of a pediatric radiographer versus a minority (23%, n=12) who expressed disapproval (Figure 8). The difference between the two groups is statistically significant with a p value of 0.0001.

Discussion

The results from this study indicate a high level of interest from radiographers as reflected in the high response rate with 67% of them making comments. The least interest was from the nursing profession as shown in the results. It is interesting to observe that despite the high interest from radiographers and the subject falling mainly under their domain, the limited literature available and some of the studies done on this subject are mainly from nursing professionals [3,6,11,15]. Regardless of these contradictory interest roles, the study attempted to shed some light on an area which seems to have received little attention over the years. A review of the responses indicated that children are quite apprehensive when in planning and on the machines at the beginning of their therapy. The majority of respondents expressed anxiety and lack of relaxation as factors that might affect precise positioning for treatment accuracy resulting in time wastage during high workloads. Most of them showed some doubt as to the effectiveness of the current methods used to calm children in radiotherapy, with sedation being singled out in most comments as an additional cause of distress to the child and parents. Mock treatment set-ups after radiation therapy planning emerged as a very popular way to help children in radiotherapy. However most respondents still favored the creation of a post of a pediatric radiographer as one way of dealing with this problem.

The study points to an interesting situational problem in radiotherapy. Thus in view of the conditioned associations between medical stimuli and discomfort, children may be fearful and uncooperative when encountering novel medical equipment and procedure [3]. In the oncology department where radiation therapy is a commonly used modality to treat certain pediatric malignancies [11], this problem might be difficult to deal with. Their fears and anxieties may be caused by meeting strangers, separation from parents, exposure to the sights and sounds of the radiation equipment, and association with previous painful medical procedures [3]. However, for radiographers to optimally treat a child's tumor while sparing normal developing tissues from both short and long-term side effects, the child must be in a fixed and reproducible position on the treatment table [11]. Reason being that the growing tissues of children are especially vulnerable to adverse radiation effects, making precision positioning extremely important [12]. Complicating the situation further is the requirement for the procedure to be undertaken while the child is alone in the treatment room. Few children can achieve

these positions when left alone room unless they are psychologically and emotionally psyched, since they may be too frightened or too young to understand what they are told [12]. The treatment of children requires an intersection of art and technique, whereby the personalities of the radiation therapist and other team members may make an enormous difference [12]. Only those persons who have the patience and understanding to deal with young patients should undertake the responsibility since some people are particularly adept at dealing with children [12,1].

When the results of this study were compared with comments from a mini-survey of staff views (n=14) at the Wessex Radiotherapy Center in the United Kingdom [1] where the idea of a paediatric radiographer has been tried, they were found to be consistent. Although the study population used in this study was

heterogeneous in terms of work characteristics and exposure similar to the one used at the Wessex Radiotherapy Centre [1], those who might not have been familiar with some situations beyond their speciality were taken care of by the "Not sure" category box provided beside some questions to account for these differences and thus avoid distortion of results. However no significant differences emerged in the overall trend of the results when the two sets of responses were analyzed separately. The study failed however to account for the different age groups since very young children, especially those under age three, may almost require sedation daily for a course of radiotherapy [2,11]. This is in contrast to those who are approximately five years of age, where sedation may be required only rarely [2]. The study might also have been affected by recall bias since most of the questions required staff to

remember incidences when they interacted with children in the department. This seems to be confirmed by the results where 36% of the respondents could not remember a particular age group of any child that might have presented intriguing problems. The study also failed to account for children who are acutely ill or in too much pain for any meaningful cooperation to be realized since the status of their disease may demand that sedation or anaesthesia be used to expedite treatment [3]. There was also no question in the questionnaire to test the reliability of the respondent, so as to exclude those who might not have taken the exercise seriously and thus guessed some responses [8]. An important point also worth noting is that though the sample size used was sufficient in the department where this study was conducted, the findings accrued may not be applicable to oncology departments in other hospitals. The latter may be operating under different economic and social-cultural conditions thereby camouflaging different perceptions in the opinions and experiences of staff. Neither did the study solicit views from the parents and children alike, who were indirectly the main subjects in the study, nor was the chi-square test supplemented by further statistical analysis to determine if other factors [13] might have operated in the observed results. All these factors might have impacted negatively on the validity of the findings in this study.

Nevertheless, the most favorable intervention to solve the problem of motion control was mock treatment set-ups. Furthermore, a review of the comments indicated that most respondents felt adequate play time should be allocated to the child. Time should be available to familiarize the child with the department and staff in order to gain the child's trust and cooperation, emphasizing that this has been practiced but not often. Others went as far as suggesting the use of distraction techniques, such as videotapes with appropriate music, use of auditory cueing (ability to distinguish time by means of length of song/story), and reproducing the same environment using familiar objects like own teddy bear or favorite toy. It is interesting to note that a few studies report similar attempts to tackle this problem in other areas. Results and data support the use of operant conditioning during Magnetic Resonance Imaging scans which takes at least 20 minutes or more to teach children to cooperate resulting in movement

reductions and thereby minimizing the need to use of sedation [14]. This method has been used to reduce movements in individuals with neurological disorder [3]. Therefore despite the benefits that can be accrued from the presence of a pediatric radiographer, the use of behavioral training seems to yield the most favorable results.

At the John Hopkins Center of Radiation Oncology this technique has been used to teach cooperation and motion control to preschoolers (3-5 years) including older children with developmental delays, a history of behavioral problems, and those who are severely anxious due to previous medical experiences [3]. Outcome data for 10 children who went through the program suggests 8 out of the 10 (80%) cooperated with radiation treatments without the need for repeated sedation or anaesthesia [3]. The approach appeared to be helpful across a variety of radiation therapy programmes, such as craniospinal, ear cranium, chest, total body irradiation, and required positioning, namely, prone, supine, lateral [3]. The disadvantage of this technique is that it requires scheduling practice sessions during which the child goes to the treatment area on one or more occasions before actual radiotherapy simulation and treatment [15]. Outcome data for 11 children at the same center who underwent a more refined behavioral training programme using miniature video displays showed 9 out of the 11 children (81.8%) completed successfully all their radiation planning and treatment sessions [15]. For most of these children the intervention only required one behavioral training session before beginning actual radiation planning and treatment [15]. This session can be scheduled the same day the imaging for treatment planning is to begin [15]. A review of the literature also supports mock treatment set-ups for children who are exceptionally apprehensive, since going through the 'dry run' procedure, may, reassure the child and make subsequent visits easier [12,16].

Thus in a busy department the child's cooperation is essential as it allows a smooth passage of treatment, reducing stress levels of staff and other patients who find it distressing if children are upset [1]. The findings in this study albeit with limitations, showed support for the creation of the post of pediatric radiographer among other suggestions not only by

radiographers, but by consultants, registrars, mould room radiation technologists, and professional oncology nurses. This may be an indication that something should be done about this issue despite the limited number of children seen in any radiotherapy department per year [1]. The issue is not how many children are seen, but how many of these children present problems and how do we deal with the issue. Thus considering the increased risks and costs associated with sedation and anaesthesia [3] it is preferable to avoid these approaches to motion control whenever possible.

Therefore borrowing a leaf from the John Hopkins Center, this study recommends the use of a behavioral psychologist who should initially work with staff during the first one or three sessions of radiation therapy before the behavior management routine is transferred to the radiation oncology nurse and therapist [3]. Thus a pediatric radiographer or any person deemed fit by the department can well fit in this position. Since as observed at the John Hopkins Centre, when staff become increasingly skilled in behavior management, the number of patients who require help from the psychologist decreases [3]. Though the practical implications of this post have to be addressed together with the contentious issue of training versus who should be trained as per the findings of this study. Of additional importance during these hard times of economic reform, is the consideration of the cost of sedation/anaesthesia for an entire course of therapy compared with the costs of a behavioral psychologist, pediatric radiographer, and use of distraction techniques. Since in the United States, the costs of materials required for the video display apparatus is modest (US\$ 650 dollars) in relation to the costs of sedation or anaesthesia for a single child's course of radiation treatment (US 13 000 dollars) [14].

This study used an indirect way of assessing the magnitude and impact of this problem. Thus a study is recommended where a questionnaire would be given to staff to fill in their observations for each child they encounter during their usual duties in the department. This might be a more reliable way of deriving data that can be used for the drawing up of a protocol for the care and reduction of motion movement in pre-school children undergoing radiation treatment where applicable. This could reinforce the current methods already in place because any one

particular case may always depend on age and the socio-cultural background of the child. Though this should not be construed to mean passive research in this matter, since as noted by Chesney and Chesney [17] children presenting problems do not just make a radiographer's work difficult, they may carry the marks the experience has scored upon them psychologically long after they have left the hospital. The findings in this study may probably be one way in dealing with this matter.

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