Research Report

A study to assess the effect of education about radiotherapy on distress among cancer patients receiving radiotherapy

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ABSTRACT

Objective: In a course of acute illness and hospitalisation, patients face many threatening events and unfamiliar procedures can be a source of emotional distress to the patients. The cause of this distress could include the fear of the unknown and/or the patient's belief that the event is potentially hazardous in terms of pain or discomfort, embarrassment, and/or adverse events. Rising healthcare costs, a shortage of nurses, and the multiple demands on staff nurses make it imperative to demonstrate that cancer education programs are useful and address patients' information needs. The primary aim of this study was to identify distress experienced by patients undergoing curative radiotherapy treatment for the first time at Central West Cancer Care Centre (CWCCC), Orange. Furthermore, this study aimed to determine if nurse education to patients after simulation will better alleviate the distress experienced by patients.

Methods: This prospective one-group before and after study design recruited 39 participants who had been prescribed curative radiotherapy treatment protocol for the first time as a treatment modality for their cancer using convenience sampling. Distress was measured by using two self-administered tools, the Distress Thermometer (DT) and the Hospital Anxiety and Depression Scale (HADS), on two separate occasions (pre and post intervention). Intervention in the form of nurse education on radiotherapy was done after the first set of data and demographic variables were collected. Changes in distress was assessed by repeating the administration of the same questionnaires at the start of radiotherapy treatments, with Wilcoxon signed rank tests used to assess significance.

Results: Distress Thermometer scores dropped from a mean of 4.44 (± 2.42) to 2.36 (± 0.4), a change that was significant ($p<.00001$). Anxiety scores from the HADS significantly dropped from 6.69 (± 2.31) to 4.62 (± 1.9) ($p<.00001$), as did HADS depression scores going from 4.08 (±2.97) to 2.77 (±2.4), ($p<.00001$). Demographic variables demonstrated no difference across DT scores, with significant reductions in DT scores regardless of age, gender, education levels, distance to treatment or numbers of radiotherapy sessions.

Conclusion: This study has found that nursing education help alleviate the degree of anxiety and emotional distress among radiotherapy participants after receiving nursing education on radiotherapy. Decreases in distress were significant across all demographic measures, demonstrating the value in nursing education for this group of patients. Depression scores also decreased, however it should be noted the number of patients with depression was very low (n=5). Radiotherapy services should continue to measure distress and anxiety, and incorporate nursing-led education strategies early in the patient's radiotherapy journey to improve patient care and patient experience.

Keywords: Radiotherapy, nursing education, distress, anxiety, rural

INTRODUCTION

Cancer patients face many threatening events during the course of their illness. One potentially threatening event is treatment with radiotherapy (Poroch, 1995). It is estimated that more than half of those diagnosed with cancer will receive radiotherapy at some stage of their cancer journey (Long, 2001).

Patient education is one of the critical components of patient care for oncology outpatients receiving radiation therapy (RT). It includes education of patients and families about the disease process, diagnostic procedures and treatment goals, and clarification of information to assist with treatment decisions as well as counselling regarding psychosocial issues (Shepard and Kelvin, 1999). Specific information regarding simulation, administration of the treatment schedule, and treatment side effects must be included (Shepard and Kelvin, 1999). Patient education is an expectation and a major component of the oncology nurse's role and is labour intensive (Porter, 1998). Despite the significant amount of nursing time spent educating patients, for the most part, very little is known about the impact of this education (Shepard and Kelvin, 1999).

Psychosocial distress occurs in one-third to one-half of all cancer patients (Chochinov, 2001; Leopold et al., 1998; Stiegelis, Ranchor and Sanderman, 2004). Approximately half of all people with a cancer diagnosis will undergo radiotherapy at some stage of their cancer treatment (Long, 2001). Misconceptions regarding the efficacy and safety of radiation therapy are prevalent among the general public and these beliefs can compound patients' fears leading to anxiety and distress about this highly precise and sophisticated modality of cancer treatment.

According to National Comprehensive Cancer Network (NCCN), distress in cancer is defined as a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment (NCCN, 2016). Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (NCCN, 2016). The term distress was chosen because it is more socially acceptable and less stigmatizing than “psychiatric,” “psychosocial,” or “emotional”, it is less likely to cause embarrassment and can be defined and measured by self –report.

It is important that patients are well informed about the aim of Radiation Therapy (RT) and misperceptions should be eliminated as it not only increases the cooperation between the patient and medical staff, but also because talking often reduces the anxiety that ascends from specific, unknown and uncontrollable situations. Cancer patients should be screened for distress during the treatment and patients with significant distress must be identified and treated proactively to avoid future psychosocial problems

(Leopold et al., 1998; Stiegelis, Ranchor and Sanderman, 2004; Roth and Modi R, 2003; Zabora, Loscalzo and Weber, 2003; Chow, Tsao and Harth, 2004).

Early interventions in cancer patients are not only effective but also economical. Therefore, routine screening programs to asses patient distress, anxiety and depression should be established (Zabora et al., 2001; Keller et al., 2004; Carlson and Bultz, 2003). Screening of patients' distress should be performed during diagnostic and therapeutic procedures to provide effective psychosocial support during RT. Use of a distress inventory like: Brief Symptom Inventory (BSI), Hospital Anxiety and Depression Scale (HADS), General Health Questionnaire, QoL Questionnaires and distress thermometer (Carlson, 2003) before, during and after the course of RT is common as it provides health personnel a better insight into patient's crisis and helps provide patient-specific-interventions.

Common interventions like education, cognitive-behavioural training (group or individual), supportive therapy (group or individual) (Carlson, 2003) are useful in alleviating distress. Education is effective during the diagnosis/pre-treatment period, when patient searches for information. It is economical and beneficial in improving patient's side effects and psychosocial outcomes (Carlson, 2003; Šprah, 2004)

Despite emphasis being laid on the importance of information, many studies reveal that a large proportion of patients have inadequate knowledge about radiotherapy. Patients may also have misconceptions about losing hair, getting radioactive, ability to drive or other concerns unrelated to radiotherapy. Studies have revealed that most patients receiving radiotherapy express a desire for more information about radiotherapy as they have inadequate information about treatment and providing such information can be helpful in relieving emotional distress. Kugaya et. al. (2000) examined patients with head and neck cancer to assess their psychological distress (adjustment disorders or major depression) or other psychiatric problems by structured psychiatric interview before the initial cancer treatment. The results suggested that out of the subjects, 16.8% had an adjustment disorder or major depression. 33.6%, 6.5%, and 32.7% met criteria for alcohol dependence, alcohol abuse, and nicotine dependence, respectively. It was concluded that head and neck cancer patients should be assessed so that psychological distress can be detected and intervention made Kugaya et. al. (2000).

Long (2001) aimed to give insight into the experience of an intensive course of radiation therapy. The purpose of this article was to describe and interpret the experiences of individuals undergoing radiation therapy in the cancer centre of a large teaching hospital. The philosophic basis was hermeneutic phenomenology and drew on the experiences described by individuals undergoing radiation therapy through a series of unstructured interviews. The findings indicated information and preparation for radiation therapy was often inadequate or did not meet the needs of the individuals in this study. Participants continue to adopt a "sick" or "patient" role even though they attend treatments on an outpatient basis, which resulted in a feeling of not being in control. Coping styles of the participants varied and were not clearly identified and assisted by relevant health professionals. Care was not always well coordinated between the various health professionals, resulting in the patient receiving mixed or confusing messages about their treatments.

In 1983, Jacobs et. al. conducted two prospective, controlled studies to determine if psychological and social functioning could be enhanced in patients by either education or participation in a peer support therapy group. The study concluded that education represents an effective, efficient, and inexpensive means of improving psychological and social behaviour in patients.

There are several studies that have assessed the anxiety and effect of different types of educational interventions in newly diagnosed cancer patients having radiotherapy. Poroch (1995) conducted a quasi-experimental study to test the effectiveness of patient education in reducing anxiety and patient satisfaction during course of radiotherapy. The results indicated that the experimental group was significantly less anxious and more satisfied than their counterparts in the control group, and the effects were maintained throughout the treatment period of up to 7 weeks.

In another prospective, randomized pilot trial conducted by Pruitt et. al (1993). conducted an educational intervention for newly-diagnosed cancer patients undergoing radiotherapy with the hypothesis that the intervention would reduce psychological distress. Psychological distress was measured at study entry, and one and three months later. It was found that the intervention group's mean scores on the depression subscale fell over the three months on study, while those of the control group rose.

McQuellon et. al (1998) tested a brief orientation program for reducing anxiety, depressive symptoms, and overall distress in cancer patients at their initial clinic visit. One hundred and fifty patients were randomly assigned to an intervention or usual care control group. The intervention group received a clinic tour, general information about clinic operations, and a question and answer session with an oncology counsellor. It was found that there were no statistically significant clinical or demographic differences between groups at initial assessment. At follow-up, the intervention group had lower state anxiety, lower overall distress, and fewer patients reporting depressive symptoms. Patients in the intervention group demonstrated significantly more knowledge about clinic operations and greater satisfaction with care. The data provides evidence that anxiety, distress and depressive symptoms can be reduced with an orientation program.

Rainey (1985) studied patients undergoing their first course of radiotherapy by assigning them to one of two patient education conditions as they entered treatment: patients in the high-information condition were shown an audiovisual program, presenting procedural and sensory information about radiotherapy;

patients in the low-information condition received standard care without exposure to the patient education program. Outcome variables, assessed during the first and last weeks of treatment (T_1 and T_2, respectively) included ratings of treatment-related knowledge, state anxiety, and total mood disturbance. Preparatory patient education produced positive results regardless of coping style. Patients in the high-information condition showed significantly greater treatment-related knowledge (at T_1) and less emotional distress (at T_2).

In order to test the efficacy of various information inputs, Haggmark et. al. in 2001 randomized 210 cancer patients equally to one of three information conditions before the start of curative radiation treatment: (1) standard information plus group and repeated individual information, (2) standard information plus brochure, and (3) standard information only. Patients completed questions regarding satisfaction with information, anxiety, depression, subjective distress and quality of life at inclusion, and 1 hour before the start of the radiation therapy treatment (approximately 4 weeks later). Patients receiving standard information plus group and repeated individual information were significantly more satisfied with the information than were patients in the remaining two groups. It was concluded that the nurses group and individual information was of significant importance in preparing the patients for the procedure of receiving radiation therapy.

D'haese et. al. (2000) to improve the provision of information to their radiotherapy patients, examined whether the timing of given written information has an effect on anxiety and satisfaction. Two sources of information were used. Sixty-eight patients were randomized to a simultaneous-information group ($n = 31$) and a stepwise-information group ($n = 37$). The stepwise-information group was significantly less anxious before simulation ($p = 0.02$) and more satisfied ($p = 0.001$). It was concluded that the provision of patient information in a stepwise format leads to less treatment-related anxiety and greater patient satisfaction among radiation therapy patient undergoing simulation.

Elshamy (2016) conducted a quasi-experimental, prospective study with the aim to assess the effect of implementing a pre-chemotherapy education programme on psychological distress of newly diagnosed breast cancer women and their carers. A total of 63 eligible adult women newly diagnosed with breast cancer were randomized to the study group (n=32) and the control group (n=31). There were no significant differences at baseline between groups for any of the characteristics. It was concluded that providing education to patients before the start of therapy prepares them for treatment and, in the long term, could improve coping strategies when dealing with the illness. Also, this approach could assist patients in avoiding unnecessary side effects and lead to improved patient outcomes.

Patients attending radiotherapy at CWCCC travel an average distance of 210 kms. This is a well above distances travelled by patients in metropolitan areas and is above the NSW Health goal for 95% of the population to reside within 100 kilometres of a radiation centre (Butler, 2014). The travelling and stay away from home whilst receiving radiotherapy in itself can be a cause of emotional distress and financial stressors for individuals receiving radiotherapy (Mercuri, 2005; Martin-McDonald, 2003).

As can be seen from the above studies, education can help reduce distress if delivered prior to treatment starting, however in rural people receiving radiotherapy there is the additional psychological stress of travel. Therefore, since this combination of stress or is has not been studied previously this study sought to explore whether a psychological intervention/education could identify and reduce distress in people undergoing radiotherapy for the first time in light of the additional stress burden of travel and dislocation from community.

AIM

The aim of this study was to identify distress experienced by patients who will undergo curative radiotherapy treatment protocol for the first time at Orange, New South Wales, as a treatment modality for cancer. Furthermore, this study aims to determine if nurse education to patients after simulation will better alleviate distress experienced by patients.

Objectives:

The primary objective of this study was to assess the level of distress experienced by patients after their simulation.

Secondary objectives were:

1. Determine if nurse education after simulation helps alleviate distress among participants.
2. To find out the association between level of distress and selected demographic variables.

METHOD

Study Design:

This study was conducted using a prospective quasi-experimental (before and after) design. A single group design was used as research had already indicated a beneficial effect from educational input and as a result a control group presented significant ethical challenges.

Ethics

Ethics was approved by the Greater Western Human Research Ethics Committee, project number HREC/17/GWAHS/43.

Setting:

This study was conducted at Central West Cancer Care Centre (CWCCC) which is the major radiotherapy referral centre for western NSW.

Hypothesis:

The following hypothesis (H) informed the study, with the null hypothesis (H0) as stated below:

H – There is a decrease in the level of distress among the participants after receiving nursing education on radiotherapy than before receiving nursing education.

H0 – There are no changes in the distress levels of participants before and after receiving nursing education.

Research population:

The participants for this study were patients who underwent curative radiotherapy treatment protocol for the first time at CWCCC-Orange. Consecutive patients who met the inclusion criteria and had given their written consent to be a part of this study were recruited to the study, with the sample size dictated by the available time for recruitment and number of eligible participants. Participants were recruited for the study using a convenience sampling technique.

Eligibility criteria:

Potential participants were considered for this study if they met the following eligibility criteria:

- Patients undergoing radiotherapy for the first-time
- 18 years old and above
- Patients who have agreed to undergo curative radiotherapy treatment protocol
- Patients attending radiotherapy as outpatients.
- Have Eastern Cooperative Oncology Group (ECOG) status 2 or less (Appendix 1).

Potential participants were excluded if they met any of the following criteria:

- Palliative or terminally ill patients
- Inability to give informed consent
- Patients who have limited understanding of English
- Oncological emergencies (eg. Spinal cord compression) or other urgent treatment
- Patients having orthovoltage treatments

- Having visual impairments that could affect their ability to read.

Recruitment and consent procedure:

Patient information was accessed from medical software currently in use at Radiation Oncology Unit, CWCCC, Orange) to determine which patients meet the inclusion criteria. A CWCCC staff member with no involvement in the trial generated a list of patients who meet the selection criteria for this study on a weekly basis. The list showed the date of simulation, full name, and patient’s contact information.

Patients who attend the CWCCC for radiotherapy treatment represent a broad geographical area, covering all of the Western New South Wales Local Health District. At the time of data collection, Radiation Oncologists were conducting their assessments in clinics in Orange, Dubbo and Bathurst. As a result of this introducing the research project and obtaining consent face to face was not always possible. The lead researcher contacted the patients via telephone once they had consented to radiation treatment and prior to their radiotherapy simulation. The lead researcher provided eligible patients with research information and answered questions raised by patients and/or their family. If the patient indicated that they were interested in the study, the lead researcher mailed, e-mailed or faxed (depending on patient’s preference) the participant information sheet and written consent form to the patient. The patients returned the completed forms when they present for their radiotherapy simulation.

Patients were assured that there would be no consequences in terms of their treatment or future health care should they choose to withdraw from the study, with their radiotherapy continuing as normal and education from nurses as per current practice. After consent was obtained, patients were enrolled into the study.

Data Collection:

After simulation at CWCCC participants were given two self-administered tools: Distress Thermometer (DT) and Hospital Anxiety and Depression Scale (HADS) to assess their level of distress (see Appendix 2). After completion of the tools, nursing education was provided to the participants. Written information was provided about radiotherapy, exercises, skin care and specific type of cancers using publications from the Cancer Council and eviQ, an online resource of cancer treatment protocols specific to the Australian context. One set of Standard Adult General Observations (SAGO) along with malnutrition screening, patient’s weight and mobility status were recorded. Participants who scored 4 or more on the DT (n=22) were offered assistance from an oncology counsellor/social worker. All of the above procedures occurred as per standard practice.

When the participants re-presented to CWCCC for their first radiotherapy treatment, 1-3 weeks after simulation, the DT and HADS were re-administered to re-assess the level of distress before their first treatment.

Instrument used:

It is standard practice within CWCCC to use DT as a screening tool for distress. The DT is a self-administered tool, with 0/10 as the equivalent of no distress and 10/10 as the equivalent of extreme distress (Appendix 2). The DT has been validated and used in to assess distress in oncology patients (Carlson, 2003).

Another tool that has been validated and used in several studies to assess the level of distress in Oncology patients is the HADS (Carlson, 2003). The HADS is a fourteen-item scale that generates ordinal data. Seven of the items relate to anxiety and seven relate to depression. Each item on the questionnaire is scored from 0-3 and this means that a person can score between 0 and 21 for either anxiety or depression with a cut-off point of 8/21 for anxiety or depression.

Demographics:

The baseline characteristics including age, gender, type of cancer, level of education, distance travelled, ECOG status of the patient and number of treatments were collected from patients and their medical notes.

Data Analysis:

Collected data from the participants was analysed and summarised. Data analysis was conducted by a statistician using SPSS software which generated descriptive statistics. Wilcoxon signed ranks test was used to compare the pre and post DT and HADS score. Wilcoxon signed ranks test was used to find the association between the level of distress and selected demographic variables.

RESULTS

In total 39 people were enrolled into the study. Demographic variables are described in Table 1.

Table 1: Classification of Respondents by Demographic variables (n=39)

Demographic variable		**n (%)**
Age		20 (51)
	< 65 years	19 (49)
	≥65 years	
Gender		15 (38.5)
	Male	24 (61.5)
	Female	
Level of education		

School	15 (38.5)
Uni, TAFE, other	24 (61.5)
Distance travelled for treatment	
≤100 kms	16 (41)
>100 kms	23 (59)
Mobility status (ECOG)	
0	31 (79.5)
≥1	8 (20.5)
Number of treatment days	
≤ 30 days	26 (67)
> 30 days	13 (33)

Of the total participants (n=39), 20 (51%) were under 65 years of age and 19 (49%) were 65 years or older. The mean age of the participants was 63 years (± SD=11.2). Fifteen participants (38.5%) were males and 24 (61.5 %) were females. Participants who had a university degree, attended TAFE or had other higher qualifications made up to a total of 24 (61.5%) and the remaining 15 (38.5%) only attended school. More than half of the participants (59%) travelled over a 100 kms and the other 16 (41%) travelled up to a 100 kms to get to the treating facility. Nearly a fifth (19.5%) of the participants had an ECOG score of at least 1 and the remaining 31 (79.5%) participants had an ECOG score of zero. Finally, only a third of the total participants (13, 33%) had more than 30 radiotherapy treatments.

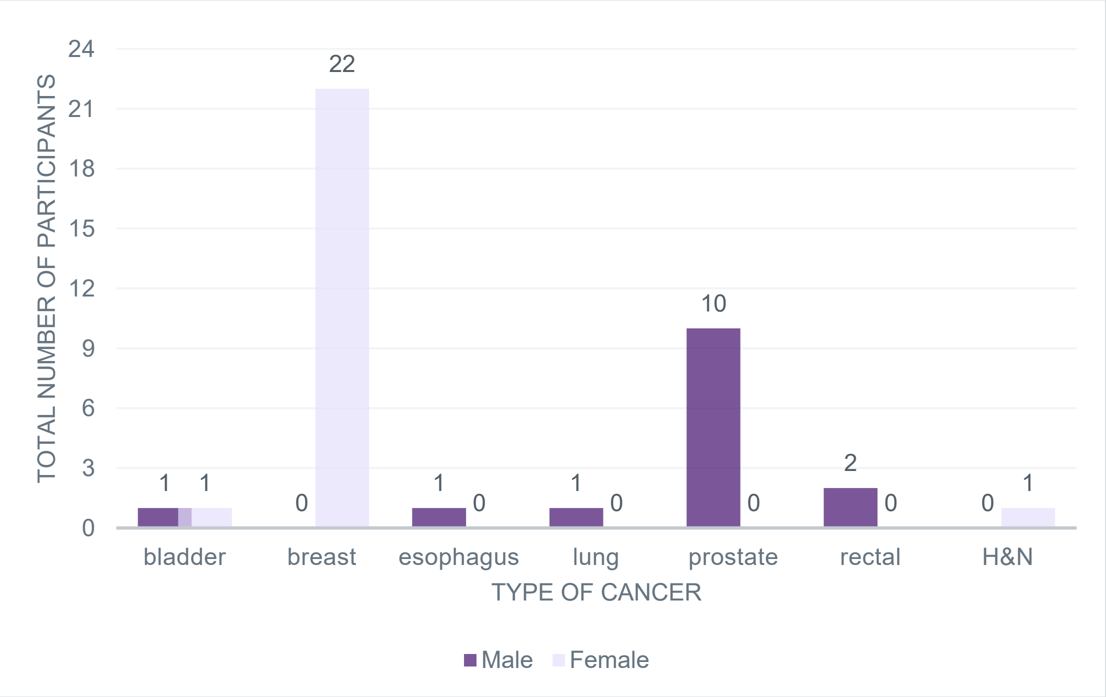

Figure 1: diagnosis by gender (n=39)

The preceding graph (Figure 1) depicts the diagnosis of the participants versus gender. The majority (n= 22) of participants study were females with breast cancer, followed by men with prostate cancer (n=10). Of the total participants there were 2 males with rectal cancer and 1 male participant each with bladder, oesophagus and lung cancer. There was only 1 female participant each with a bladder cancer and head and neck cancer diagnosis.

Figure 2 demonstrates pre-education score for distress, anxiety and depression. It is notable that 22 people (≈56%) reported having moderate to severe distress (≥4 on DT) post radiotherapy simulation and prior to receiving education. Furthermore, 14 participants (≈36%) and only 5 participants (≈ 13%) scored 8 or more for anxiety and depression respectively. This indicates that after the radiotherapy simulation, more than half of the study participants reported having moderate to severe distress and more than a third of the study participants reported being anxious. However, only a small percentage of people reported feeling depressed.

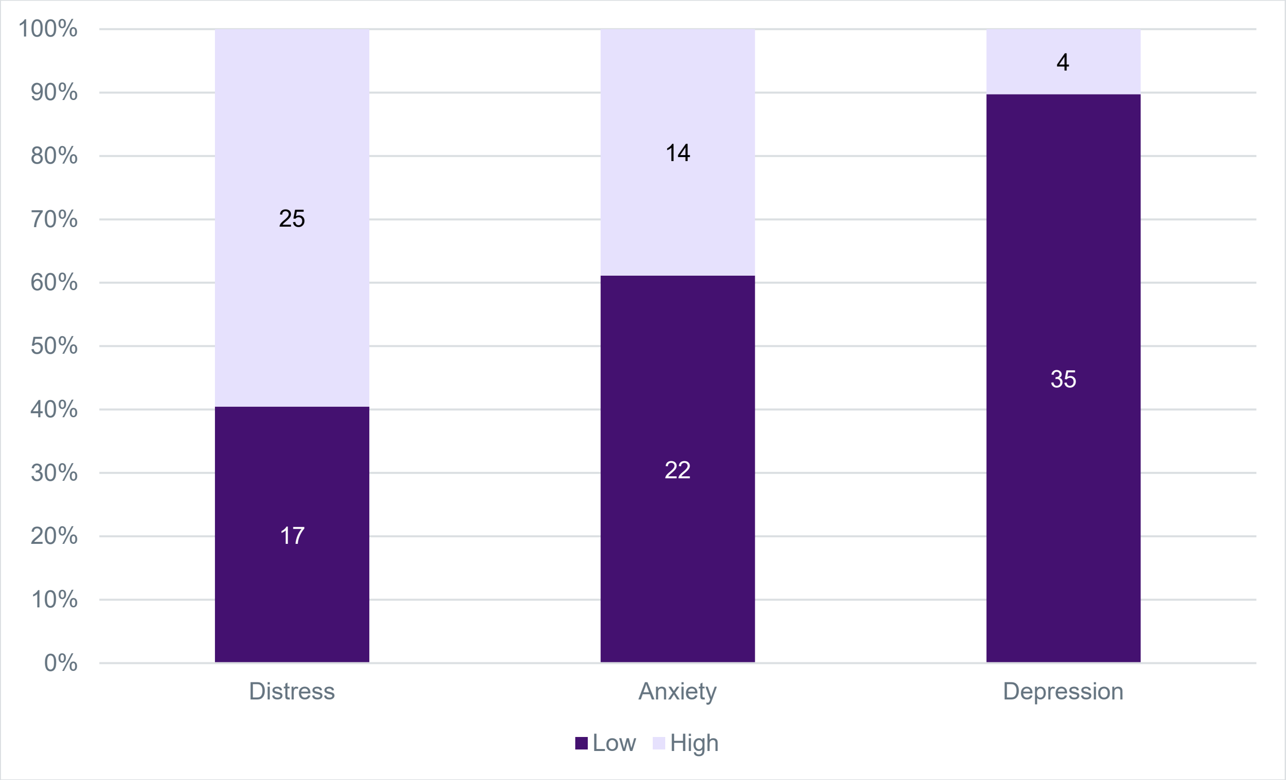

Figure 2: Pre-education scores for distress (low if <4), anxiety (HAS, low if <8) and depression (HDS, low if <8)

Table 2 shows mean and median scores before and after nursing education. There was significant reduction in distress, anxiety and depression scores. Reduction also occurred in scores for practical, physical and emotional problems, while there was no change in reported family problems.

Table 2: Mean, standard deviation, mean percentage and change in levels of distress, anxiety and depression after nurse education

Measures	**Pre**		**Post**		**Change**		**Z**	**p***
	Mean (SD)	**Median**	**Mean**	**Median**	**Mean**	**Median**		
Distress Thermometer	4.44 (2.42)	4	2.36 (2.0)	2	-2.08 (0.4)	2	-5.25	< .00001
Practical problems	0.51 (0.79)	0	0.28 (0.5)	0	-0.23 (0.3)	0	-2.49	.006
Family problem	0.21 (0.46)	0	0.21 (0.5)	0	0 (0)	0	0	.5
Emotional problem	1.77 (1.54)	1	0.95 (1.1)	1	-0.82 (0.4)	0	-4.09	.00002
Physical problem	3.82 (3.21)	3	2.62 (2.6)	2	-1.2 (0.6)	1	-3.3	.0005
Hospital Anxiety Scale	6.69 (2.31)	7	4.62 (1.9)	5	-2.07 (0.4)	2	-5.22	< .00001
Hospital Depression Scale	4.08 (2.97)	3	2.77 (2.4)	2	-1.31 (0.6)	1	-4.3	< .00001

*Wilcoxon signed rank test

Table 3 explores the association between the level of distress and demographic variables. With age, participants were divided into two main categories. For those aged under 65, there was statistically significant improvement on their DT, practical problems, emotional problems, physical problems, HAS and HDS scores. For the participants aged 65 and above, there was statistically significant improvement in their DT, emotional problems, physical problems, HAS and HDS scores. However, practical problems remained unchanged in this group. In either groups (ie <65 or ≥65), there were no changes in the scores for Family and spiritual problems.

Table 3: Distress, anxiety and depression per demographic variables

Descriptive			**DT**	**Practical**	**Family**	**Emotional**	**Spiritual**	**Physical**	**HAS**	**HDS**
Age	< 65 years	*z*	-3.76	-2.49	0	-2.94	0	-2.49	-3.78	-2.5
		p	<0.001	0.013	1	0.003	1	0.013	<0.001	0.012
	≥65 years	*z*	-3.71	0	0	-2.88	0	-2.27	-3.65	-3.46
		p	<.001	1	1	0.004	1	0.023	<0.001	=0.001
Gender	Male	*z*	-3.258	-1.732	0	-2.762	0	-1.779	-3.209	-2.783
		p	0.001	0.083	1	0.006	1	0.075	0.001	0.005
	Female	*z*	-4.153	-1.897	0	-3.092	0	-2.87	-4.164	-3.499
		p	<0.0001	0.058	1	0.002	1	0.004	<0.0001	<0.0001
Education	School	*z*	-3.499	-1.414	0	-2.762	0	-2.212	-3.197	-3.238
		p	<.00001	0.157	1	0.006	1	0.027	0.001	0.001
	Uni/TAFE/Other	*z*	-4.011	-2.111	0	-3.086	0	-2.447	-4.179	-2.829

		p	<.00001	0.035	1	0.002	1	0.014	<.00001	0.005
Distance	≤100 kms	*z*	-3.325	-1.732	-0.577	-1.983	0	-2.175	-3.457	-2.808
		p	0.001	0.083	0.564	0.047	1	0.03	0.001	0.005
	>100 kms	*z*	-4.096	-1.897	-1	-3.63	0	-2.524	-3.958	-3.272
		p	<.00001	0.058	0.317	<.00001	1	0.012	<.00001	0.001
ECOG	0	*z*	-4.647	-2.333	0	-3.461	0	-2.874	-4.681	-3.566
		p	<.00001	0.02	1	0.001	1	0.004	<.00001	<.00001
	≥1	*z*	-2.546	-1	0	-2.333	0	-1.62	-2.388	-2.388
		p	0.011	0.317	1	0.02	1	0.105	0.017	0.017
Total treatments	≤30 days	*z*	-4.421	-2.309	0	-3.451	0	-2.95	-4.346	-3.378
		p	<.00001	0.021	1	0.001	1	0.003	<.00001	0.001
	>30 days	*z*	-2.87	-1	0	-2.251	0	-1.615	-2.979	-2.733
		p	0.004	0.317	1	0.024	1	0.106	0.003	0.006

Within Table 3, the association between level of distress to the gender of the participants can be seen. Among both males and females, statistically significant improvement was observed in their DT, practical problems, emotional problems, physical problems, HAS and HDS scores. In either group, there were no changes in the scores for Family and spiritual problems.

The above Table 3 also compares the association between level of distress to the level of education of the participants. The participants were divided into people who had attended school and people who had attended university/TAFE or had other degrees. In both groups, there was statistically significant improvement on their DT, practical problems, emotional problems, physical problems, HAS and HDS scores. No changes were seen in the scores for Family and spiritual problems in either group.

When exploring the association between level of distress to the distance travelled by the participants to treatment, participants were categorized into people who travelled 100 kms or less and people who had travelled over 100 kms to get to CWCCC (see Table 3). In the group travelling >100km, there was a statistically significant improvement on their DT, practical problems, emotional problems, physical problems, HAS and HDS scores. While a negative effect was seen in the scores of family problems this was not statistically significant. In the <100km group, the DT, practical problems, family problems, emotional problems, physical problems, HAS and HDS scores improved. However, no changes were observed in the scores of spiritual problems in either category.

Table 3 compares the association between level of distress to the mobility status (ECOG) of the participants. Here the participants were divided into two groups based on their mobility status (ECOG). i.e. people who had an ECOG score of zero and people who had an ECOG score of 1 or more. Statistically significant improvement was seen in the DT, practical problems, emotional problems, physical problems, HAS and HDS scores of both groups. However, no changes were seen in the scores for Family and spiritual problems in either group.

As seen in Table 3, the association between level of distress to the total number of radiotherapy treatments received by the participants was explored. Here the participants were grouped as: people who had radiotherapy for 30 days or less and people who had more than 30 days of radiotherapy. There was statistically significant improvement on the DT, practical problems, emotional problems, physical problems, HAS and HDS scores of all participants and their Family and spiritual problems' scores remained unchanged.

DISCUSSION

There is an expectation with any oncology education program that it should increase patient's knowledge by providing relevant information in a simplified manner (Jahraus, 2002). In this case the decrease in the pre and post DT and HADS scores suggests that there is a decrease in the level of distress among the participants after receiving nursing education on radiotherapy. There are multiple factors such as the fear of the unknown and/or the patient's belief that the event is potentially hazardous in terms of pain or discomfort, embarrassment, adverse events, travelling and stay away from home whilst receiving radiotherapy and similar other factors which can cause distress among patients receiving radiotherapy. The analysis of the distress thermometer revealed that 56% of the participants reported having moderate to severe distress and the HAS score suggests that more than a third of the study participants reported being anxious post radiotherapy simulation. There was a significant decrease in the DT and HAS scores after the nursing education, demonstrating an encouraging response to nursing education in the areas of distress and anxiety.

The study results indicate that patient education in a radiation therapy setting can help alleviate the degree of anxiety and emotional distress experienced by patients undergoing curative radiotherapy treatment, potentially through increasing patients' treatment-related knowledge. The intervention consisted of face to face nurse education with the participants in conjunction with written information about radiotherapy, exercises, skin care and specific type of cancers using Cancer council booklets and Eviq publications. All of this was done after radiotherapy simulation and it has yielded measurable improvements in the patients' level of distress.

Distress and anxiety if left unaddressed can lead to a loss of trust in care givers, disbelief in the efficacy of treatment, and dissatisfaction with the care received (Poroch, 1995). The long-term consequences of these effects are unknown; however, there can be serious implications for the quality of life especially when patients relying on radiotherapy as a hope for cure.

The HDS collected from the participants study indicates that only a small proportion (13%) of the participants were identified with depression after radiotherapy simulation. Literature suggests that up to 36% of cancer patients suffer depression (Pasik, 1998). The effects of depression on functions such as sleep, energy, and motivation intensify weight loss and fatigue. Depression also can potentially exacerbate treatment-related side effects, leading to a vicious circle that not only may worsen depression and increase disability, but also affect disease control (Chen, 2008). This study did not look specifically into depression experienced by participants, however more research about depression among people having radiotherapy will be beneficial.

A comparison of the different types of cancers among the participants and the gender of the participants shows that of the total 39 respondents (15 males and 24 females), 22 (92%) women had breast cancer and 10 (68%) men had prostate cancer. Oesophageal, head and neck and lung cancers comprised of 2.6% of the participants each and bladder and rectal cancers each attributed to 5.1% of the participants. This distribution of patients across various cancer streams in the study is reflective of the actual patient distribution at CWCCC as breast and prostate cancer radiotherapy treatments constitute a majority of the treatments provided at CWCCC.

Due to the small sample size of this study (n=39), all demographic characteristics (age, gender, level of education, distance travelled for treatment, mobility status and number of treatments), were only categorized in to 2 sub-groups. The findings of this study revealed that out of the selected demographic variables, while all showed significant reductions in distress, none of the variables have shown any significant association with the levels of distress. Thus regardless of the differences in their demographic characters, the participants of this study had a lower post DT and the post HADS scores compared to their pre DT and the pre HADS scores. This may indicate that nurse education can be seen to be helpful across ages, gender and levels of education.

Limitations

This study had a small sample size, was a one group before and after design and used a convenience sampling technique to recruit participants, all of which can be considered limitations. There is no information about the levels of distress of patients after their initial consultation with the radiation oncologist. The participants of this study were outpatients who had curative radiotherapy treatment for their cancer. The effect of nursing education on the distress levels of inpatients and palliative patients having radiotherapy at CWCCC is unknown.

Conclusion

This study has found that nursing education help alleviate the degree of anxiety and emotional distress among radiotherapy participants after receiving nursing education on radiotherapy. Decreases in distress were significant across age groups, gender, level of education of the participants, distance required to travel for treatment, patient mobility or the number of radiotherapy treatments the patient required. Reductions in anxiety mirrored these distress results, demonstrating the value in nursing education for this group of patients.

The findings of this study demonstrate the value in measuring distress and anxiety for radiotherapy patients and proactively addressing this distress with education. Radiotherapy services should continue to incorporate nursing-led education strategies early in the patient’s radiotherapy journey to improve patient care and patient experience.

Recommendations

- The study be replicated on large samples to validate and generalize the results, potentially with a control group receiving routine care to understand the trajectory of patient distress while having radiotherapy and the effectiveness of nurse education in reducing patient distress.
- Further research to be conducted to look in to depression scores of people undergoing radiotherapy and the role of nursing education for people with depression who are undergoing radiotherapy.
- Consideration for measurement of distress in other populations outside of the radiotherapy setting.

Acknowledgements

This project was supported through the NSW Health Education and Training Institute (HETI) through the Rural Research Capacity Building Program.

The author expresses his gratitude and sincere appreciation to the following people who have been instrumental throughout this project:

David Schmidt and Kerith Duncanson, Rural Research Capacity Building Program Officers, Health Education and Training Institute (HETI) – for all of their ongoing support, encouragement and advice, allowing me to complete this research project.

A/Prof Catherine Hawke, A/Deputy Head of School, School of Rural Health, Orange Campus, Audley Clinic, The University of Sydney – your knowledge, support, advice and assistance throughout this project has been invaluable.

Dr Georgina Luscombe, from the University of Sydney, for statistical support and interpreting results

Orange Health Service, especially Edite Soks, Nurse Unit Manager, Cancer Services for assisting me with finding and rostering backfill hence enabling me to complete the project and supporting my participation in the Rural Research Capacity Building Program.

Western NSW Local Health District – for their support of my research project and for their ongoing support of the Rural Research Capacity Building Program.

All Radiation Oncology staff of CWCCC, Orange – for their collegial support and assistance with the data collection and assisting with backfill of my position.

Phil Sanders Research governance officer and Frances Guiness, Librarian, Orange Health services for all their support and guidance.

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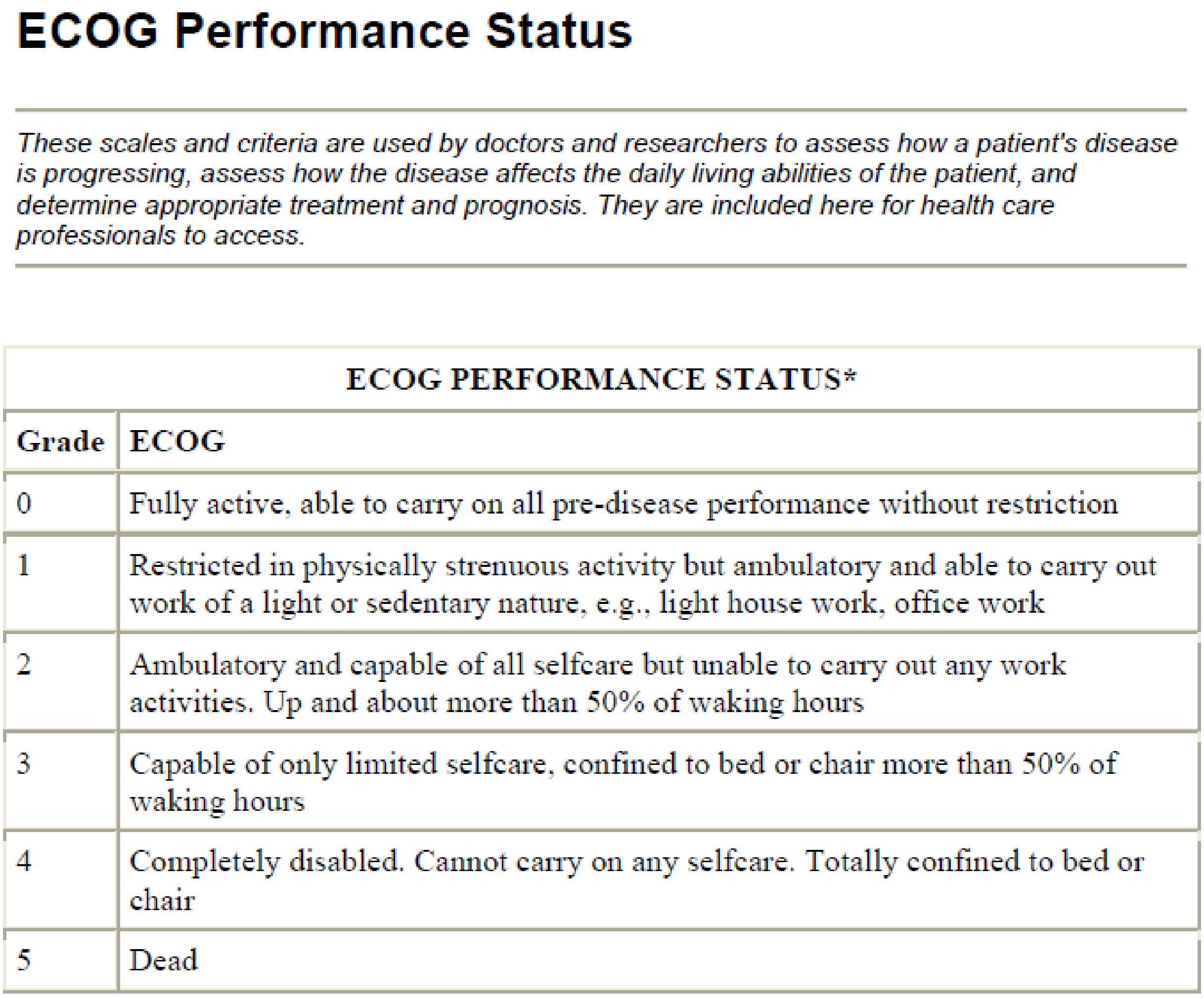
APPENDICES

Appendix 1: ECOG scale



ECOG Performance Status

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here for health care professionals to access.

ECOG PERFORMANCE STATUS*

Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

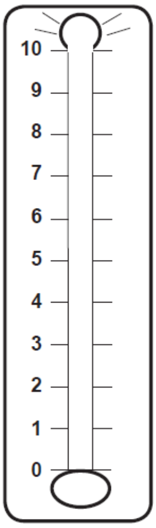
Appendix 2: Distress thermometer and Hospital Anxiety and Depression Scale

NCCN National Comprehensive Cancer Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.



PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

YES NO Practical Problems

☐ ☐ Child care
☐ ☐ Housing
☐ ☐ Insurance/financial
☐ ☐ Transportation
☐ ☐ Work/school
☐ ☐ Treatment decisions

Family Problems

☐ ☐ Dealing with children
☐ ☐ Dealing with partner
☐ ☐ Ability to have children
☐ ☐ Family health issues

Emotional Problems

☐ ☐ Depression
☐ ☐ Fears
☐ ☐ Nervousness
☐ ☐ Sadness
☐ ☐ Worry
☐ ☐ Loss of interest in usual activities

☐ ☐ **Spiritual/religious concerns**

YES NO Physical Problems

☐ ☐ Appearance
☐ ☐ Bathing/dressing
☐ ☐ Breathing
☐ ☐ Changes in urination
☐ ☐ Constipation
☐ ☐ Diarrhea
☐ ☐ Eating
☐ ☐ Fatigue
☐ ☐ Feeling swollen
☐ ☐ Fevers
☐ ☐ Getting around
☐ ☐ Indigestion
☐ ☐ Memory/concentration
☐ ☐ Mouth sores
☐ ☐ Nausea
☐ ☐ Nose dry/congested
☐ ☐ Pain
☐ ☐ Sexual
☐ ☐ Skin dry/itchy
☐ ☐ Sleep
☐ ☐ Substance abuse
☐ ☐ Tingling in hands/feet

Other Problems: ____________________

____

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Chart I — Hospital Anxiety and Depression Scale

This questionnaire will help your physician know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important. Mark only one answer for each question.

A (1) I feel tense or wound up:
3 ( ) Most of the time
2 ( ) A lot of times
1 ( ) From time to time
0 ( ) Not at all

D (2) I still enjoy the things I used to:
0 ( ) Definitely as much
1 ( ) Not quite so much
2 ( ) Only a little
3 ( ) Hardly at all

A (3) I get a sort of frightened feeling as if something awful is about to happen:
3 ( ) Very definitely and quite badly
2 ( ) Yes, but not too badly
1 ( ) A little, but it doesn't worry me
0 ( ) Not at all

D (4) I can laugh and see the funny side of things:
0 ( ) As much as I always could
1 ( ) Not quite as much now
2 ( ) Definitely not so much now
3 ( ) Not at all

A (5) Worrying thoughts go through my mind:
3 ( ) Most of the time
2 ( ) A lot of times
1 ( ) From time to time
0 ( ) Only occasionally

D (6) I feel cheerful:
0 ( ) Most of the time
1 ( ) Usually
2 ( ) Not often
3 ( ) Not at all

A (7) I can seat at ease and feel relaxed:
0 ( ) Definitely
1 ( ) Usually
2 ( ) Not often
3 ( ) Not at all

D (8) I feel as I am slowed down:
3 ( ) Nearly all the time
2 ( ) Very often
1 ( ) From time to time
0 ( ) Not at all

A (9) I get a sort of frightened feeling like butterflies in the stomach:
0 ( ) Not at all
1 ( ) From time to time
2 ( ) Quite often
3 ( ) Very often

D (10) I have lost interest in my appearance:
3 ( ) Definitely
2 ( ) I don't take so much care as I should
1 ( ) I may not take quite as much care
0 ( ) I take just as much care as ever

A (11) I feel restless, as if I had to be on the move:
3 ( ) Very much indeed
2 ( ) Quite a lot
1 ( ) Not very much
0 ( ) Not at all

D (12) I look forward with enjoyment to things:
0 ( ) As much as I ever did
1 ( ) A little less than I used to
2 ( ) Definitely less than I used to
3 ( ) Hardly at all

A (13) I get a sudden feeling of panic:
3 ( ) Very often indeed
2 ( ) Quite often
1 ( ) From time to time
0 ( ) Not at all

D (14) I can enjoy a good TV or radio program or book:
0 ( ) Often
1 ( ) Sometimes
2 ( ) Not often
3 ( ) Hardly at all