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In this issue

Editorial

The *AJCN* aims to provide a forum where debate and the exchange of views can take place. We welcome papers on contemporary professional policy or practice issues of concern and interest to cancer nurses.

Notes for contributors

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Guest editorial
The cancer nurse–dietitian alliance in the era of COVID-19

Why the role of nurses in the nutritional care of patients must not be undervalued

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Few would disagree that life has changed unequivocally over the past 18 months. As the COVID-19 pandemic has evolved, most of us have endured altered lifestyles, mental health, financial stability and social relationships. For many, the work arena has changed as well. Remote workplaces, expanded role demands, increased specialisation and an increased reliance on technology have become the new reality. In healthcare, these changed work roles have been even more pronounced. Redeployment, rapid retraining, overtime shifts, increased workplace pressures and overarching mental exhaustion have become the new norm. Healthcare workers have attracted a new level of societal respect, with constant accolades for all that they are achieving on the COVID frontlines.

Little attention, however, has been focused on the healthcare demands existing in parallel to COVID care, which do not cease to exist because of COVID's bullishness. Services that already provide complex, specialised care are now doing so in the context of altered staffing, new service delivery models and changing levels of patient engagement[1,2]. This is particularly evident in the cancer arena, where the disease continues to tout its presence, worldwide pandemic or not! For many, the overwhelming fear of 'catching COVID', so often fuelled by relentless and alarming media reportage, has trumped the presence of any worrying symptoms, and led to delayed presentation for cancer screening, testing and diagnosis[3,4]. Subsequently, more cases of advanced and often terminal disease are occurring, and with them greater risk of malnutrition[5]; malnutrition which, in this current COVID-19 ravaged existence, has become increasingly difficult to manage by conventional means.

Malnutrition in cancer patients is serious, with the severity reflecting the hypermetabolic nature of the disease, cancer location and impact of treatment on appetite, food intake and nutritional tolerance[6]. Furthermore, self-imposed dietary restrictions, as patients desperately experiment with alternative 'cancer' diets, can also contribute to malnutrition rates, ultimately compromising longer-term treatment success and survival outcomes[7].

It is therefore imperative that malnutrition be effectively managed to optimise patient outcomes and maintain quality of life. This need is already well recognised, with dietitians occupying an important role in the multidisciplinary team. Nutritional monitoring is routinely integrated into standard care, with patients undergoing regular nutrition screening, receiving targeted nutrition education, and being provided with therapeutic diets to assist in the management of nutrition-related symptoms. Anthropometry, biochemistry and psychosocial parameters are frequently monitored, and comprehensive nutritional pathways are followed to help optimise outcomes for this highly vulnerable patient group. The physical presence of dietetic staff in the cancer setting is an invaluable part of these processes.

Since the emergence of COVID-19, it has been more challenging to execute timely and targeted nutritional care. Dietitians, like most other health practitioners, have had to change their patient management practices as they adapt to continually evolving public health scenarios. With institutional mandates limiting direct patient contact, dietitians have had to reduce their physical presence in the cancer setting, necessitating a shift to using telephone and email for patient screening, assessment and monitoring. Inter-professional collaboration and communication is now relying primarily on technology, and patient themselves are being given greater power when it comes to the reporting of anthropometrical measures, symptom severity and food intake.

While dietitians have adapted well to this change in practice, success has been reliant on a strengthened collaboration with

nursing staff. This is a challenge in itself, as dietitians, already conscious of the existing demands of cancer nursing, have attempted to afford nutritional care an appropriate degree of priority without imposing additional burden or damaging the much-valued nursing–dietetic alliance.

Within the multi-disciplinary healthcare team, nurses work collaboratively with dietitians to provide nutritional care for cancer patients with the aim of optimising patient outcomes. With nurses typically the first point of contact for patients in the cancer care setting, it is the strong, trusting relationships that patients develop with their nurses that supports them through, and often defines, their cancer journey. Being a liaison point between the patient and family during times of admission, nurses have ready access to information such as normal feeding practices, food preferences, cultural and religious avoidances, food allergies, intolerances and home nutrition histories. This information is paramount to the delivery of appropriate food service and supports the comprehensive assessment and targeted nutritional care provided by the dietitian.

As coordinators of patient care, nurses also collect and communicate clinical data that directly impacts the identification of nutritional risk and the implementation of supportive care. The meticulous reporting of patients' height and weights, fluid intake, hydration status and bowel output form the basis of dietetic reviews. Furthermore, accurate and consistent food charting provides dietitians with the means of making meaningful assessment of calories, protein and other key nutrient intake. Nutritional screening, as well as timely reporting of cancer-related symptoms such as nausea, vomiting, dysphagia, dry mouth, mucositis or low mood, can also alert the dietitian to the need for supportive therapeutic dietary manipulations and education.

Holding responsibility for the practical administration of enteral feeding support, nurses are also in the position to ensure that prescribed dietetic feeding regimes are closely adhered to and disruptions or unnecessary alterations to feeds are minimised. Likewise, nursing staff have a valuable role when it comes to encouraging patients with the consumption of oral nutrition support. Timely provision of charted Med-Pass programs, and encouraging patients with the consumption of prescribed supplement drinks or nutritious protein/energy snacks are a powerful means of supporting nutritional health.

Over the last decade the challenges faced by many patients with the physical task of feeding has gained increased attention[8]. For many, navigating a bed or chair to easily access meal trays, the manipulation necessary to open packets or cut up food, or simply the task of moving food from plate to mouth can prove very difficult. While much is done at dietetic, food service and institutional levels to address such issues, nursing staff are also in a prime position to intervene. Ordering cut-up/open packet or appropriately textured diets, clearing bedside trays before meal delivery, and providing set up and feeding assistance to vulnerable patients is essential in helping optimise nutrition outcomes. Advocating for protected meal times and minimalised meal disruptions, while also monitoring and acting upon unnecessary extended periods of nil-by-mouth, can also prove a valuable consideration for nutritionally vulnerable patients[9].

Thus, while the COVID-19 pandemic is undoubtedly a health crisis, an increasing appreciation of the valuable role that nursing staff play in nutritional care of cancer patients has emerged. As the roadmap out of COVID remains unclear, and with the continuation of telehealth and strict infection control protocols remaining a reality, nurturing a strong and collaborative dietitian–nursing alliance remains imperative as we work towards managing the nutritional outcomes of this vulnerable patient group.

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Cancer Nursing Workforce Mapping project: the most important survey you'll do this year

As the peak professional body for cancer nursing, the CNSA strives to promote excellence in cancer care through the professional contribution of cancer nurses. We know that cancer nursing is changing, and that understanding this workforce is paramount to our vision of best possible outcomes and experiences for all people affected by cancer.

It is for this reason that we have launched the Cancer Nursing Workforce Mapping project. This significant piece of research aims to:

- Understand who and where cancer nurses in Australia are, and to identify their needs.
- Describe the cancer nursing workforce using a mixed-methods approach to collect, synthesise and collate data regarding cancer nurses in Australia.
- Comprehensively map the cancer nursing workforce in Australia, providing valuable information that can be overlayed with cancer incidence data and used for workforce planning and development.

This is the first time a national survey will provide a comprehensive picture of the working conditions and professional concerns of nurses who work exclusively in cancer care and control.

We believe this is our most important survey to date and encourage all nurses working with cancer patients to be involved.

Project benefits

Workforce planning will enable CNSA to identify opportunities for advocacy and to predict employment needs. Understanding the needs of the workforce will also inform education strategies, succession planning, recommended caseloads data and future requirements of cancer nursing to meet the needs of the Australian population.

Nurses informing nursing workforce strategies is vital to the development of our profession, and we're all in this together. We want to know who you are, where you're based and what you need to succeed. This data set will enable government and partnership opportunities, guide policy development, and help shape our influence in years to come.

National demographics will help inform our policy and advocacy efforts as we push for equity of access to care, the need for nurses to work to the top of their scope, and strategic planning for cancer services focused on holistic care needs of patients and family, including specialist cancer and haematology nurse positions.

Find out more about this important project and complete or share the survey today: www.cnsa.org.au/workforce

Cancer Nurses Society of Australia

Scanxiety and tumour marker-related anxiety in people with cancer: experiences of genitourinary cancer nurses

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Abstract

Aims To explore genitourinary cancer nurses' perceptions of scan-associated anxiety ('scanxiety') and tumour marker-related anxiety in people with cancer.

Methods A purpose-designed cross-sectional survey used Likert scales to assess perceived prevalence, severity and contributing factors for scanxiety and tumour marker-related anxiety, and nurses' comfort discussing scan procedures and results. An open-ended question asked how scanxiety could be improved.

Results The response rate was 49% (34/70). Most participants believed scanxiety occurred 'quite' (41%) or 'very' often (35%). All perceived scanxiety severity to be at least 'moderate'. Waiting for results was the leading contributing factor to scanxiety. Recommendations to minimise scanxiety included: reducing waiting times; patient education; improved communication; and practical and psychological support. Participants perceived tumour marker-related anxiety occurred 'quite a bit' (35%) or 'very much' (59%) and 50% thought it was 'severe'.

Conclusion Cancer nurses commonly see people with cancer who experience test anxiety and have valuable insight into anxiety-reducing strategies.

Introduction

People with cancer experience higher rates of anxiety and depression than the general population[1]. Investigations to assess the progress of their cancer are essential components of cancer care, and can have profound implications on their treatment and prognosis. However, this anxiety in people with cancer may be heightened when these investigations are performed, such as around the time of imaging scans or serum tumour marker tests (e.g., prostate-specific antigen [PSA]). The distress experienced by people with cancer leading up to, during and after a radiological scan for cancer was first dubbed 'scanxiety' by a cancer survivor writing for the USA *Time* magazine in 2011[2].

Scanxiety is recognised and acknowledged by cancer organisations through news articles about clinician experiences with scanxiety[3] or about self-management strategies on how to cope with scanxiety[4,5]. These articles are typically based on personal experiences rather than formal assessment or evidence-based interventions. A systematic scoping review on scanxiety in people having cancer-related scans found over half of studies were in people who were having screening scans, with a wide

range of scanxiety prevalence between 0–83% (Bui, submitted). However, to date, in people with cancer, there is only limited published research on scanxiety. A study of 103 people with non-small cell lung cancer identified "scan-associated distress" in 83% of participants[6]. Another study in 30 lymphoma survivors found the majority had increased anxiety and fear of recurrence of their cancer around the time of computed tomography (CT) scans[7]. There is also scarce literature on tumour marker-related anxiety, with research often focused on the clinical utility of tumour markers such as which tumour marker or what frequency tumour markers should be used or have been used in the clinical care of breast, colon and ovarian cancers[8–13].

In particular, PSA-related distress or anxiety has been reported in 53% to 76% of men with prostate cancer[14,15]. This tumour marker-related anxiety can influence treatment; Mahal et al.[16] found that amongst men with a biochemical recurrence of prostate cancer, those with high levels of PSA anxiety were twice as likely to receive salvage androgen deprivation therapy as men who did not have high levels of PSA anxiety. However, the survival benefit of using androgen deprivation therapy in this setting is unclear[17,18] so it is possible that some men with high levels of tumour marker-related anxiety are receiving unnecessary treatment.

Cancer nurses are likely to observe scanxiety and tumour marker-related anxiety in people with cancer and are therefore well-placed to help reduce these anxieties. The primary aim of this study was to explore the experiences of genitourinary cancer nurses with scanxiety, and to identify nurse-led strategies that may reduce scanxiety. The secondary aim was to explore the experiences of genitourinary cancer nurses with tumour marker-related anxiety, particularly as these nurses were highly likely to interact with men with prostate cancer who undergo regular PSA monitoring.

Methods

We invited genitourinary cancer nurses to complete a self-administered, purpose-designed cross-sectional survey exploring their experiences with scanxiety and tumour marker-related anxiety in people with cancer. Using convenience sampling, the population was genitourinary cancer nurses attending the Australian and New Zealand Urogenital and Prostate Cancer Trials Group Nurses Symposium in Brisbane, Queensland, Australia on 21 July 2019. The survey was available in hardcopy and electronically via the conference app. Consent was implied by return of the survey. The study was approved by the local ethics committee.

The survey (Appendix 1) was developed in consultation with medical oncologists and a behavioural psycho-oncologist who all had experience in scanxiety research. It consisted of 30 items divided into three parts. The first part focused on scanxiety. Participants were asked if they had heard about or seen scanxiety in people with cancer. Using 5-point Likert scales, participants rated: how often they perceived scanxiety to occur; how severe they perceived scanxiety to occur in the average person with cancer; and how comfortable they were performing tasks such as booking scans, providing scan education, arranging Port-A-Cath access for scans, assisting with difficult cannulation, providing scan results via telephone, email or print-out, and discussing scan results face-to-face. Five-point Likert scales were also used for participants to rate the importance of several factors that may contribute to people experiencing scanxiety: pre-existing anxiety or depression; feeling supported by family and/or friends; the process of booking a scan; intravenous access for contrast for a scan; the scan procedure; and waiting for the results of a scan. These potential contributing factors were derived from focus groups run by the research team with people with advanced cancer and with healthcare professionals (HCPs)[19]. An open-ended question asked participants how scanxiety could be reduced in people with cancer.

The second part of the survey focused on tumour marker-related anxiety. Using 5-point Likert scales, participants were asked to rate: how often they perceived tumour marker-related anxiety to occur; its perceived severity in the average person with cancer; and how comfortable they felt providing people with their tumour marker results. The third part asked participants their age, length of time working in oncology, and how likely they were to: provide education about scans; book scans; and discuss scan and tumour marker results with people with cancer.

Hardcopy surveys were distributed to genitourinary cancer nurses at the start of the Nurses Symposium and collected at the end. An accompanying participant information sheet included a web link to an electronic version of the survey. Descriptive statistics were generated using R Version 3.6.1[20]. Open-ended questions underwent content analysis for common themes.

Results

Characteristics of respondents

The survey was completed by 34 of 70 eligible genitourinary cancer nurses attending the symposium, an overall response rate of 49%. All participants completed the survey in its entirety, except for one participant who did not complete the question about contributing factors to scanxiety.

Participants had a median age of 50 years (range 29–66 years) and had worked in oncology for a median of 6 years (range 1–35 years). Almost all participants (97%, 33/34) worked with men with prostate cancer. Eleven participants (32%, 11/34) worked with people with other types of genitourinary cancers including kidney, bladder and testicular cancers.

Participants were 'quite a bit' or 'a lot' involved with: patient education about scans (82%, 28/34); booking scans (44%, 15/34); discussing scan results with people with cancer (74%, 25/34); and discussing tumour marker results with people with cancer (85%, 29/34).

Prevalence and severity of scanxiety

Most participants had heard about or seen scanxiety in people with cancer (85%, 29/34). Of these, most perceived scanxiety to occur 'quite often' (41%, 14/29) or 'very often' (35%, 12/29). All participants believed scanxiety occurred at least at 'moderate' severity in the average person with cancer. Eight participants (28%) believed scanxiety occurred at 'severe' levels and one participant believed scanxiety occurred at 'extremely severe' levels (Table 1).

Factors contributing to scanxiety

Participants perceived that 'waiting for the results of a scan' (94%, 31/33) and 'pre-existing anxiety or depression' (82%, 27/33) contributed 'quite a bit' or 'a lot' to scanxiety. Most participants indicated 'feeling supported by family and/or friends' (76%, 25/33), 'the process of booking a scan' (64%, 21/33), 'the scan procedure' (64%, 21/33), and obtaining 'intravenous access for contrast for a scan' (55%, 18/33) contributed at least 'moderately' to scanxiety (Figure 1).

Cancer nurses' level of comfort performing scan-related tasks

Participants were more likely to be 'quite a bit' or 'very' comfortable' booking scans (62%, 21/34) and explaining what is involved in a scan (91%, 31/34) than they were arranging Port-A-Cath access for a scan (44%, 15/34) or assisting with difficult cannulation (35%, 12/34).

Participants were 'not at all' comfortable conveying scan results by phone (42%, 14/33), email (70%, 23/33) or print-out (48%, 16/33) before patients discussed the result with their oncologists in a follow-up consultation, while 29% (10/34) were 'quite a bit' and 62% (21/34) were 'very' comfortable discussing scan results after the oncologist consultation. Some participants indicated that discussing results of scans was outside the scope of their role, and emphasised they would not discuss results until the doctor had discussed them with patients.

Table 1. Perceived prevalence and severity of scanxiety and tumour marker-related anxiety in people with cancer

	Scanxiety (n=29)*	Tumour marker-related anxiety (n=34)
Prevalence n (%)		
Hardly at all	0 (0)	0 (0)
Somewhat	0 (0)	0 (0)
Moderately	3 (10)	2 (6)
Quite often	14 (41)	12 (35)
Very often	12 (29)	20 (59)
Severity n (%)		
Very mild	0 (0)	0 (0)
Mild	0 (0)	0 (0)
Moderate	19 (66)	14 (41)
Severe	8 (28)	17 (50)
Extremely severe	1 (3)	3 (9)

* 5 of 34 participants had never heard about or seen scanxiety in people with cancer

Reducing scanxiety

Twenty-five out of 34 respondents completed an open-ended question about reducing scanxiety. Content analysis identified five key recommendations – reduced waiting times; education of patients and HCPs; improved communication; practical support; and psychological support. It was identified that "the unknown is a major source of concern" for patients and strategies to reduce scanxiety should develop the "human side of care". These themes are described in more detail in Table 2.

Prevalence and severity of tumour marked-related anxiety

Participants perceived tumour marker-related anxiety to occur 'quite often' (35%, 12/34) or 'very often' (59%, 20/34). In the average person with cancer, all participants perceived tumour marker-related anxiety occurred at least at 'moderate' severity, with some believing it occurred at 'severe' (50%, 17/34) and 'extremely severe' (9%, 3/34) levels.

Most participants (68%, 23/34) were 'quite a bit' or 'very' comfortable providing results of tumour markers to patients when asked.

Discussion

In this study, scanxiety and tumour marker-related anxiety were perceived by cancer nurses to occur commonly in people with cancer, and were at least of 'moderate' severity. Cancer nurses identified waiting for results of a scan and premorbid anxiety or depression as important contributing factors to scanxiety. Nurses were not comfortable discussing scan results with patients until they had discussed the result with the oncologist, and recommended reduced waiting times, education, communication, psychological support and practical supports as strategies to reduce scanxiety.

This study highlighted factors related to HCPs and healthcare systems that may reduce scanxiety, whereby the ideal approach is likely to be multifactorial and multidisciplinary. Cancer nurses have a central role in patient education and the provision of practical and psychosocial support for patients[21,22], and often lead or facilitate interventions that improve psychosocial care or self-management, provide teaching, guidance or counselling or that streamline procedures[23]. In our study, cancer nurses had good awareness of scanxiety and tumour marker-related anxiety and so are well-placed to identify and help manage scanxiety and tumour marker-related anxiety. A scoping review on scanxiety in people having cancer-related scans showed interventions to reduce scanxiety often occurred within the radiology department with assistance from nursing and radiology staff (Bui, submitted). Institutions therefore may need to define or formalise pathways for people with cancer having scans so that scan-related procedures are consistent and streamlined to minimise scanxiety and improve the patient experience. This may include patient education, optimising processes for booking scans, assisting with difficult intravenous access and rapid communication of results.

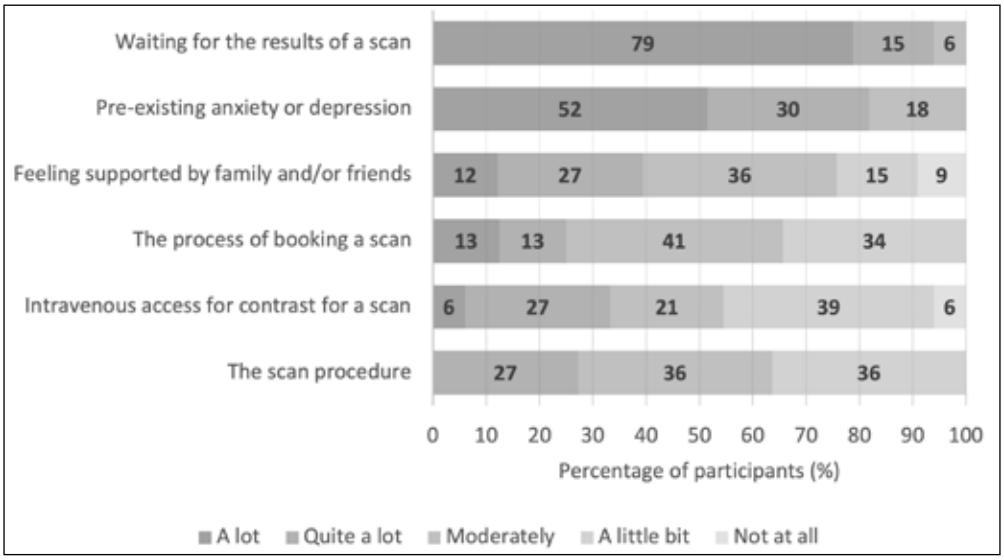

Figure 1. Perceived contributing factors to scanxiety

Table 2. Recommendations to reduce scanxiety

Key theme	Details
Reduced waiting times	At the following time points: • Between the scan and the result • In the waiting room for the scan • In the waiting room to receive the scan result Suggested methods: • Booking scan and follow-up clinic appointments close together • Oncologists calling patients with results
Education of patients and healthcare professionals (HCPs)	About: • Rationale for performing the scan • Process of the scan • Expected timeframe to receive results • Method of receiving results (e.g., phone, scheduled appointment) Provided to patients by: • Oncology HCPs; or • Radiology staff Education for HCPs about scanxiety was also recommended
Improved communication	To explain to patients: • Before the scan – the expected results and implications to management • How scans are interpreted as part of a holistic assessment • After the scan – a clear treatment plan Suggested methods for patient communication: • Giving bad news face-to-face • Using interpersonal skills, responding to cues and empathetic listening • Allowing time and privacy for communication • Formal avenue to contact oncology HCPs (e.g., phone number for urgent enquiries or for cancer nurses) Communication between HCPs (oncologists, nurses, general practitioners) was recommended
Practical support	Suggested methods: • Assisting with organising a scan • Providing clear instructions for scan preparation (fasting and contrast), travel and parking • Being a physical presence during a scan
Psychological support	Suggested methods: • Acknowledging and normalising scanxiety • Providing reassurance • Involving services of cancer nurse and/or social worker
Other	Individualised assessment of scanxiety Mindfulness, including relaxation scripts or applications

Tumour marker-related anxiety was numerically perceived to occur more frequently and at greater severity compared to scanxiety in this study. This may be due to higher frequency of PSA testing (as an objective measure of cancer activity[24]) when compared to scans. Tumour markers have variable utility in other cancers, depending on the cancer type and reason for testing (screening, diagnosis, surveillance or disease monitoring)[25,26], which may influence the frequency and severity of both tumour marker-related anxiety and scanxiety. More reliable tumour markers may reduce the frequency of scans; this may lead to higher tumour marker-related anxiety and lower scanxiety. Less reliable tumour markers may lead to increased scan frequency as a way to accurately monitor the cancer; this may have a variable impact on tumour marker-related anxiety and may increase scanxiety. The interplay between tumour marker-related anxiety and scanxiety is hence complex and requires further study.

The concept of minimising uncertainty was apparent in the strategies identified to reduce scanxiety in this study, and is consistent with qualitative research on scanxiety in focus groups in people with advanced cancer and HCPs[19]. Reducing the duration of uncertainty may be achieved by setting time-based benchmarks after a scan is performed for the provision of finalised results or the scheduling of clinic appointments with the oncologist. Further, after the oncologist has interpreted and explained the test results and their implications to patients, this discussion should be relayed to other members of the healthcare team to allow consistent communication to patients, which may also reduce uncertainty and scanxiety.

The main strength of this study was that it provided novel data about the perceptions and attitudes towards scanxiety and tumour marker-related anxiety in cancer nurses and provided practical suggestions to reduce scanxiety. Scanxiety and tumour marker-related anxiety are likely to occur whenever these investigations are used to assess the progress of a cancer; hence, the issues raised by this study will have universal reach to the multidisciplinary cancer care team.

Limitations include its small sample size with inadequate power to draw associations between scanxiety and tumour marker-related anxiety. These results may not reflect the experiences of cancer nurses who did not attend the symposium, the experiences of cancer nurses who work in areas other than prostate and genitourinary cancers, or the experiences of other HCPs, particularly in relation to other tumour streams where tumour markers are not as reliable, or not used. We also did not survey genitourinary cancer patients so we are unable to compare the nurses' responses with patient perceptions of scanxiety and tumour marker-related anxiety.

This study provides a pragmatic assessment of the experiences of cancer nurses on scanxiety and tumour marker-related anxiety and provides a starting point for future research. Priorities for future research include exploring the experiences of people with cancer to identify the magnitude of these problems, including a longitudinal assessment of how scanxiety and tumour marker-related anxiety may change over time, and the association between scanxiety and tumour marker-related anxiety. It is necessary to identify, develop and implement feasible strategies to reduce scanxiety and tumour marker-related anxiety, which may include patient-based interventions or systems-based changes to healthcare delivery. Such strategies may be founded on broadly applicable principles, but will require individualisation to each cancer service based on patient factors (e.g., cancer type and stage) and system factors (e.g., access to healthcare, resource availability).

Conclusions

Cancer nurses commonly see people with cancer who experience scanxiety or tumour marker-related anxiety. Their indispensable roles in cancer care has provided them with valuable insight into scanxiety and tumour marker-related anxiety, and into implementable strategies to reduce these anxieties.

Ethics

The study was approved by the University of Sydney Human Research Ethics Committee (2019/562).

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Conflict of interest

The authors declare no conflicts of interest.

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Appendices

Appendix 1. Scanxiety cancer nurses survey

A few questions about scanxiety:

1. Have you heard about or seen scanxiety in people with cancer?
(Please tick one of the following answers)

☐ Yes *Proceed to Question 2.*
☐ No *Proceed to Question 4.*

2. How often do you think scanxiety occurs in people with cancer?
(Please circle one option)

Rarely | Somewhat | Moderately | Quite often | Very often

3. How severe do you think scanxiety is in the average person with cancer?
(Please circle one option)

Very mild | Mild | Moderate | Severe | Extremely severe

4. Please circle how much you think the following factors contribute to scanxiety in people with cancer, where '1' means 'Not at all' and '5' means 'A lot'.

	Not at all	A little bit	Moderately	Quite a bit	A lot
Pre-existing anxiety or depression	1	2	3	4	5
Feeling supported by family and/or friends	1	2	3	4	5
The process of booking a scan	1	2	3	4	5
Intravenous access for contrast for a scan	1	2	3	4	5
The scan procedure	1	2	3	4	5
Waiting for the results of a scan	1	2	3	4	5

5. The following items may reduce scanxiety. Please circle which of these you would be comfortable performing as a cancer nurse for people with cancer, where "1" means "Not at all" and "5" means "Very comfortable".

	Not at all	A little bit	Don't mind either way	Quite a bit	Very comfortable
Before a scan:					
Booking scans	1	2	3	4	5
Explaining what is involved in the scan	1	2	3	4	5
Arranging Port-A-Cath access for a scan	1	2	3	4	5
Assisting with difficult cannulation	1	2	3	4	5
After a scan and BEFORE the follow-up appointment with the oncologist:					
Giving the scan results via telephone	1	2	3	4	5
Giving the scan results via email	1	2	3	4	5
Giving a printed report of the scan results	1	2	3	4	5
After a scan and AFTER the follow-up appointment with the oncologist:					
Discussing the results of the scan	1	2	3	4	5
Giving a printed report of the scan results	1	2	3	4	5

6. How do you think scanxiety can be improved in people with cancer?

7. People with cancer can also experience anxiety related to tumour marker results (e.g. PSA). How often do you do you think tumour marker-related anxiety is a problem for people with cancer? (Please circle one option)

Hardly at all Somewhat Moderately Quite a bit Very much

8. How severe do you think tumour-marker anxiety is in the average person with cancer? (Please circle one option)

Very mild Mild Moderate Severe Extremely severe

9. Are you comfortable providing people with cancer with tumour marker results when asked? (Please circle one option)

Not at all A little bit Don't mind either way Quite a bit Very comfortable

A few details about you:

10. Age _____ years

11. How long have you worked in oncology? _____ years

12. Do you talk to people with cancer about scans (patient education)? (Please tick one option)

- ☐ A lot
- ☐ Quite a bit
- ☐ Sometimes
- ☐ Never

13. Do you book scans for people with cancer? (Please tick one option)

- ☐ A lot
- ☐ Quite a bit
- ☐ Sometimes
- ☐ Never

14. How often do you discuss scan results with people with cancer? (Please tick one option)

- ☐ A lot
- ☐ Quite a bit
- ☐ Sometimes
- ☐ Never

15. How often do you discuss tumour marker results with people with cancer? (Please tick one option)

- ☐ A lot
- ☐ Quite a bit
- ☐ Sometimes
- ☐ Never

16. What types of cancer do the patients you work with have? (Please tick all that apply)

- ☐ Prostate
- ☐ Kidney and/or bladder
- ☐ Testicular
- ☐ Other

Conclusion

17. Do you have any other comments?

You have now come to the end of this survey. Thank you for your time and effort in completing the questions and helping us in this important study.

Cancer Nurses Society of Australia

Current practices and standards regarding provision of information to women newly diagnosed with DCIS: a national survey

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Abstract

Ductal carcinoma in situ (DCIS) is a highly prevalent pre-cancerous condition. Multiple factors affect patient outcomes, and over-treatment of DCIS is an international concern. This study aimed to examine information provision and sufficiency of existing resources to meet the needs of women with DCIS. Healthcare professionals (HCPs) on the Breast Cancer Network Australia (BCNA) national database were surveyed. Quantitative data was analysed with descriptive statistics and Chi-squared tests. In total, 132 HCPs participated. Most (55%) indicated that breast care nurses were primarily responsible for providing DCIS-related information. Cancer Australia's *DCIS* booklet (61.5%) was most commonly used. Most respondents were aware of the *My journey kit* but only half gave it to their patients. Of those that used it, 36.4% described it as suboptimal, but the best currently available. A new DCIS-specific resource is needed to ensure provision of relevant information to facilitate shared treatment decision-making.

Background

Ductal carcinoma in situ (DCIS) is a pre-cancerous condition, variously described as pre-invasive, non-invasive or Stage 0 breast cancer[1]. It accounts for >20% of screen-detected breast tumours[2]. Around 2,300 Australian women are diagnosed with DCIS annually, with incidence and absolute numbers steadily increasing over time[3]. The incidence of DCIS is 25% higher in urban than rural areas[4]. If untreated, DCIS may develop into invasive breast cancer. Therefore, the primary aim of treating DCIS is to reduce the risk of invasive breast cancer or the recurrence of DCIS.

Treatment decisions for DCIS are complex and can vary from person to person. Multiple factors affect decision-making such as age, co-morbidity, family history, breast density, breast size and shape, grade and location of DCIS, and surgical margin status[5]. Balancing these factors to achieve optimal outcomes depends on patient preferences and clinician opinions[6]. Decisions about treatment for DCIS are made more difficult by uncertainty regarding its natural history[5]. Consequently, controversy exists about optimal management of DCIS and there are significant variations in practice[6].

In Australia, treatment for DCIS varies according to individual circumstances, but may include similar treatment as that given to women diagnosed with early breast cancer such as breast surgery, radiotherapy and/or hormone therapy[7]. Over-treatment of low risk DCIS is a growing concern, with potential consequences including psychological and behavioural effects of disease labelling, reduced quality of life from unnecessary treatment, increased costs to individuals, and wasted resources to the health system[8,9].

A recent systematic review found that women diagnosed with DCIS have a number of information and support needs[5]. Women experience anxiety related to information given at

diagnosis and the complexity of decision-making. There is also lack of consistency in what women are told about prognosis and whether DCIS is, in fact, breast cancer. Women want to know what a diagnosis of DCIS means to them personally and their individual risk of developing invasive breast cancer in the future[8]. These women may over-estimate their risk of recurrence, have persistent exaggerated fears, and are dissatisfied with available information and support to make informed treatment decisions[10]. Confusion is exacerbated if patients with DCIS are given information primarily designed for early breast cancer or recommended the same treatment(s) as someone diagnosed with early breast cancer[5]. Further, evidence highlights that treatment for DCIS can affect core aspects of quality of life (physical, role, social, emotional function, pain, fatigue) and psychological distress (anxiety, depression)[11].

Several information resources have been developed for people diagnosed with DCIS[12]. The *My journey kit* is a resource developed by Breast Cancer Network Australia (BCNA) for people diagnosed with early breast cancer. It is not specific to DCIS but is often given to people diagnosed with DCIS as it describes treatment options relevant to both DCIS and early breast cancer. Other Australian DCIS-specific resources exist but have not been updated for some time or are now out of print[12].

The aim of this study was to examine the current use of resources intended to facilitate informed or shared decision-making with people diagnosed with DCIS in Australia, the awareness of available resources by healthcare professionals (HCPs), and their perceived adequacy of the existing resources. Given the significant difference in incidence rates, this study also aimed to examine any variation in information provision and resource use between HCPs in rural and metropolitan areas.

Method

Participant selection and recruitment

HCPs were eligible to participate if they were on the BCNA database. This included those who were registered for BCNA's My Care Kit program (primarily breast care nurses) or subscribed to receive BCNA's Health Professionals Update (a broad cross-section of HCPs including nurses, allied health, medical oncologists, surgeons, psychologists and GPs). An initial invitation email describing the aims of the study with the survey link was sent to 1,280 HCPs across Australia on 8 May 2017, followed by a reminder email on 18 May 2017.

This study was reviewed and approved by the University of Sydney Human Research Ethics Committee (HREC), project number 2020/746, and performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Ethical considerations were made in the design; we only collected anonymous de-identified data, and data was stored on BCNA secured servers. Data was not shared outside the study investigators or with any third party. Consent to participate was implied by completed online surveys.

Data collection

Data was collected via a survey launched through SurveyMonkey. The survey was purpose-designed to meet our study aims, and consisted of 18 closed-ended questions and six open-ended questions about:

- Information clinicians provide at the time of a DCIS diagnosis.
- Key information clinicians believe women need to receive at diagnosis.
- Clinicians' perceptions about whether women's information needs change following a diagnosis of DCIS (and how); how women like to receive information when diagnosed (e.g., format, level of detail, timing); key challenges for women diagnosed with DCIS; and factors which influence women's information needs.
- Clinicians' perceptions about limitations of currently available information resources.

Data analysis

Raw survey data was exported from SurveyMonkey into Excel for data management. Survey responses were analysed descriptively. Mean differences between responses of HCPs in rural areas (inner regional, outer regional and remote) compared to metropolitan areas (major cities) were examined through Chi-squared analysis using SPSS® Statistics for Windows® version 22.0 (IBM, Armonk, New York, USA).

Due to the limited amount of qualitative data, thematic analysis was not feasible nor meaningful. Instead, open-ended responses were summarised by topic.

Results

In total, 132 HCPs completed the survey; 109 completed the full survey and 23 did not respond beyond question seven (of 24 total questions). The majority of respondents were breast care nurses (56.8%) or BreastScreen nurse counsellors (22.0%). Other respondents included registered nurses (4.5%), oncology nurses (3.8%), practice nurses (2.3%), cancer care coordinators (2.3%) or those who selected 'other' (8.3%). Respondents were from all Australian states and territories except the Australian Capital Territory. Overall, 54.5% of respondents saw women diagnosed with DCIS in inner regional, outer regional or remote areas, while the remainder saw women in major cities. The characteristics of participants are presented in Table 1.

Current practice

The majority of respondents (55%) indicated that breast care nurses took primary responsibility for providing general information resources to patients newly diagnosed with DCIS, followed by BreastScreen nurse counsellors (17.4%) and surgeons (13.8%) (Figure 1). Responses highlighted variation in the printed

resources HCPs provided to women newly diagnosed with DCIS. The resources most commonly given by HCPs in both metropolitan and rural areas was Cancer Australia's *Ductal carcinoma in situ* booklet (61.5%), BCNA's *My journey kit* (28.4%), and the Cancer Australia booklet *Guide for women with early breast cancer* (19.3%) (Figure 2).

Barriers to provision of information

Almost half the respondents (48.6%) indicated no barriers to the provision of printed information to women newly diagnosed with DCIS at the time of diagnosis. Those that experienced barriers reported patients presenting to them at a later stage after someone else had already given them information (24.8%) or lack of suitable resources available (15.6%) as the most common barriers. The complete list of barriers to information provision can be found in Supplementary Table 1.

Awareness and use of existing resources

Overall, 48.6% of respondents were not aware of the Cancer Australia communication aid *Understanding ductal carcinoma in situ and deciding about treatment*, and 23.9% were aware of the resource, but did not use it with women diagnosed with DCIS.

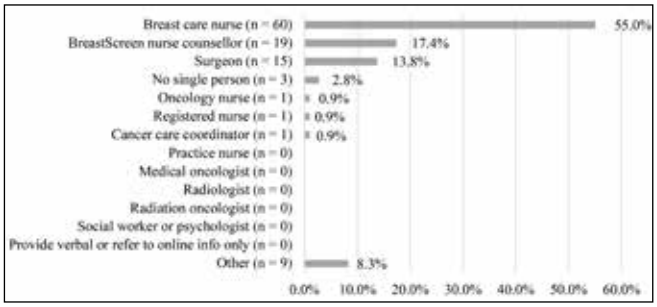

Figure 1. Number of HCPs taking primary responsibility for providing general printed information resources to people newly diagnosed with DCIS (n=109)

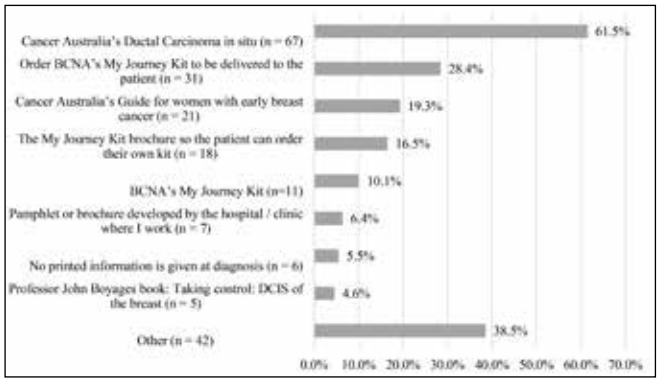

Figure 2. Type of printed information resource provided to people diagnosed with DCIS at the time of diagnosis (n=108)

Participants could select multiple responses. 'Other' includes Westmead Breast Cancer Institute's DCIS-specific information resource, information booklets developed by state or territory Cancer Councils (e.g., *Understanding Breast Cancer, Cancer Council Queensland booklet – emotions and cancer),* anatomical diagrams, leaflet produced by BreastScreen, or a book by Professor Boyage *Taking control: DCIS of the breast*

Table 1. HCP characteristics and context in which they work with people with DCIS

	Total respondents (n=132)	
Category	**n***	**%**
Professional position		
Breast care nurse	75	56.8%
BreastScreen nurse counsellor	29	22.0%
Registered nurse	6	4.5%
Oncology nurse	5	3.8%
Practice nurse	3	2.3%
Cancer care coordinator	3	2.3%
Psychologist/social worker	0	0.0%
Other	11	8.3%
State or territory		
ACT	0	0.0%
NSW	38	28.8%
NT	3	2.3%
QLD	33	25.0%
SA	13	9.8%
TAS	8	6.1%
VIC	27	20.5%
WA	10	7.6%
Main location when seeing people diagnosed with DCIS		
Major city	59	44.7%
Inner regional area	55	41.7%
Outer regional area	13	9.8%
Remote area	4	3.0%
Very remote area	0	0.0%
Not reported	1	0.8%
Main type of health service when seeing people diagnosed with DCIS		
Cancer centre or specialist breast clinic	52	39.4%
Public hospital (not cancer specialist)	21	15.9%
Private hospital	20	15.2%
Community health service	20	15.2%
Private practice	4	3.0%
GP/Primary care provider	3	2.3%
Other	12	9.1%
Approximate number of people diagnosed with DCIS seen per week		
<1 per week	52	39.4%
1 or 2 per week	61	46.2%
3–10 per week	19	14.4%
>10 per week	0	0.0%
Most common time since diagnosis that people diagnosed with DCIS are seen*		
At time of diagnosis	86	44.3%
After diagnosis and through active treatment for DCIS	70	36.1%
At time of follow-up care, where active treatment has finished but hormone therapy may continue	28	14.4%
Other	10	5.2%
Nursing experience		
Early career (1–5 years of experience)	11	8.3%
Mid-career (6–15 years of experience)	18	13.6%
Late-career (16+ years of experience)	101	76.5%
Did not specify	2	1.5%

* Participants could select multiple responses

The main reason for disuse was that the communication aid was out of print and only available online.

As for the *My journey kit,* 98.1% indicated that they were familiar with the resource but only half (52.4%) used it with women diagnosed with DCIS. Of those that used the *My journey kit*, 36.4% reported it was suboptimal for women diagnosed with DCIS, but currently the best resource available (Figure 3). Qualitative data suggests that the currently available resources did not provide accurate information about the nature of DCIS, treatment options and prognosis. Respondents were concerned about providing the *My journey kit* to women diagnosed with DCIS because it used the term 'cancer' throughout the resource and contained a section on 'How to deal with a diagnosis of cancer'. These terms were perceived as contributing to negative psychosocial impacts and fear of recurrence, and was the primary reason why respondents preferred not providing it to women diagnosed with DCIS. Ratings for the usefulness of the various core components of the *My journey kit* resource are presented in Supplementary Figure 1.

When asked whether they refer people diagnosed with DCIS to online sources for information, the majority (42.2%) said they did not. For those that did, they most commonly referred patients to resources from BCNA or websites for organisations such as Cancer Australia, the McGrath Foundation, the Breast Cancer Institute and the Cancer Council.

Differences between rural and metropolitan areas

A greater proportion of HCPs from rural (66%) compared to metropolitan areas (41%) reported they were aware of and used the *My journey kit,* while more metropolitan respondents (63%) used it with patients diagnosed with early breast cancer but not DCIS (χ^2(2, n=105)=10.25, p=0.006 (Figure 4). There was no significant difference between rural and metropolitan respondents on reasons for using the *My journey kit* and perceptions of its usefulness. However, a greater proportion of rural (42%) compared to metropolitan (15%) respondents found it 'very useful'.

New resource for women with DCIS

The majority of respondents (88.2%) believed that a new resource designed specifically for women diagnosed with DCIS would be helpful. The ideal resource would be short and easy to understand. Respondents used descriptions such as an 'A5 booklet', 'pamphlet', 'small booklet', 'compact', 'single A4 sheet', 'a short concise handout or small booklet' and 'A4 folded pamphlet'. Having the option to give patients an online or printed version of the resource depending on individual preference was preferred.

In terms of content, respondents believed that the ideal resource would be DCIS-specific and culturally appropriate. It should provide "consistent and clear" information about DCIS to "prevent confusion... and distress", including the associated risks, recommended treatment options, and the curable nature of the diagnosis. It should also normalise the emotional responses to a DCIS diagnosis, and highlight the difference between DCIS and invasive early breast cancer. Diagrams or images were regarded as useful tools to facilitate comprehension.

Discussion

The current information provision practices of Australian HCPs vary widely. Variation was found in what information was provided to women newly diagnosed with DCIS and the type of information resources given to them. Barriers to provision of information included language, communication and internet access. Cancer Australia's *Ductal carcinoma in situ* was the most commonly used resource followed by BCNA's *My journey kit*. However, HCPs only used the *My journey ki*t as it was considered the best currently available rather than the ideal information pack. There was a clear preference towards a new resource that better addressed the needs of patients following a DCIS diagnosis. The ideal resource was described as a small, concise booklet or one-page sheet that provided key, culturally sensitive information and specific to DCIS.

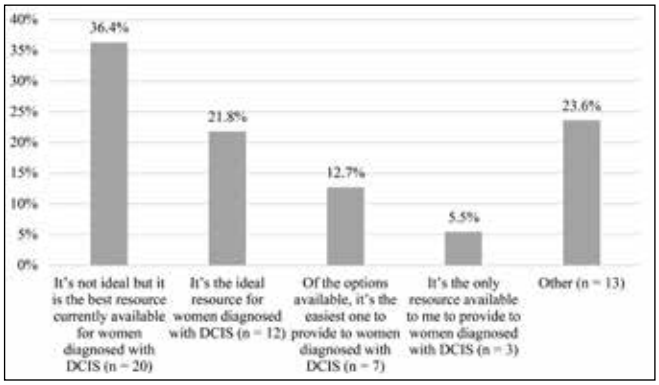

Figure 3. Respondents' awareness of BCNA's My journey kit *and use of it with people diagnosed with DCIS (n=55).*

Of the respondents who selected 'Other', four HCPs said they gave *My journey kit* to women diagnosed with DCIS because it contained sections which were relevant; however, they noted that they went through *My journey kit* with women diagnosed with DCIS to provide context and to point out the relevant/irrelevant sections.

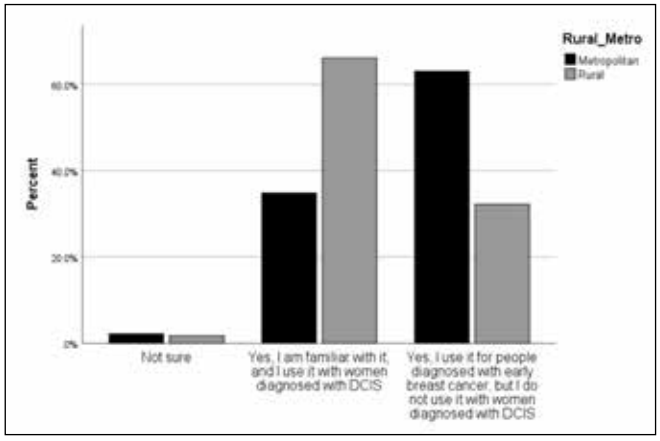

Figure 4. Proportion of rural and metropolitan HCPs who were unaware, aware and/or used the My Journey Kit *(n=105)*

The findings from this survey complement the current literature on the information needs of women newly diagnosed with DCIS. Their experiences demonstrate knowledge and information deficits, dissatisfaction with the currently available decisional support, and consequential anxiety and distress related to misconception about the condition and prognosis[5]. It is important that they understand that DCIS is not invasive and therefore less serious than early-stage invasive breast cancer. This survey highlights that HCPs are aware of patient concerns and recognise the need for a new resource that can better meet their information needs. The current resources may over or under represent the associated risks of progression or recurrence. HCPs emphasised the need for clarity and consistency around treatment options, reasons why those options may change over time for an individual, and the curable nature of the diagnoses to provide reassurance following a diagnosis of DCIS.

It is critical for decision support resources such as decision aids, information booklets and verbal information to include up-to-date evidence and information about all treatment options available as they can play an important role in a patient's decision-making[13]. Individuals who receive such resources have improved knowledge regarding their options, and reduced decisional conflict, anxiety and feeling uninformed compared to those who receive usual care from HCPs[13]. Decision support resources supplement the patient–provider interaction by promoting and facilitating shared decision-making, which is particularly important for complex treatment decisions.

Despite the importance, current resources for women newly diagnosed with DCIS facing a treatment decision are outdated. For example, the communication aid for DCIS, *Understanding ductal carcinoma and deciding about treatment*, was developed in 2009 and may not reflect current evidence or best practice[14]. The findings from this study suggest that the method of delivery for such resources is also important, but existing resources have limited options for delivery such as through an online platform.

At the time of diagnosis, women need to understand the nature of their diagnosis and feel well informed to make a treatment decision that is right for them. There are a large number of disease-specific questions that need to be answered for women to better understand the condition, and treatment-specific questions for deciding about treatment and planning ahead[5,15]. The contents of a new DCIS-specific resource should include information about these topics to ensure the identified informational needs of women diagnosed with DCIS are met.

The results of this survey will be used to inform the development of DCIS-specific content on BCNA's new *My journey* online tool. BCNA's *My journey* online tool is a digital, interactive tool that provides people diagnosed with DCIS, early breast cancer and metastatic breast cancer with access to tailored information specific to their individual circumstances and needs.

For women in rural areas, accessibility to health services and treatment options is an additional challenge. Individuals in rural areas experience poorer health outcomes, access to services, resources and treatment[16]. More specifically for DCIS, rural HCPs indicated a greater usage of the *My journey kit* in the DCIS population as well as in women diagnosed with breast cancer compared to their metropolitan counterparts. Qualitative data suggests that this may be due to fewer health services and treatment options available in rural areas. Furthermore, types of surgical procedures varies by rurality and socioeconomic status[17]. Women in rural areas are less likely to receive radiation therapy following breast conserving surgery than those in metropolitan areas[18]. Further research is warranted to consider equity of service and access, as well as locally available treatment options for rural women diagnosed with DCIS.

Conclusion

In conclusion, this survey highlights the heterogeneity of current information provision practice across Australia and the inadequacy of some of the information given to women at the time of their DCIS diagnosis. Currently available resources given to women at DCIS diagnosis are deemed insufficient and suboptimal as the content is not DCIS-specific. A DCIS-specific resource addressing the major questions arising from a new diagnosis and treatment option considerations will help equip women to make informed treatment decisions that are better suited to their circumstances and needs at all stages of their treatment pathway. This may also facilitate an open discussion about risks and prognosis which will contribute to maintaining the patients' physical and psychological well-being and potentially reduce unnecessary treatment.

Conflict of interest

The authors declare no conflicts of interest.

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Cancer Nurses Society of Australia

The symptom experience of patients during chemoradiation for head and neck cancer: a retrospective chart review

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Abstract

Purpose This study explored the range of symptoms and supportive care provided by the multidisciplinary team in patients with head and neck cancer (HNC) undergoing concurrent chemoradiation therapy (CRT).

Methodology A retrospective chart review of two electronic medical records was conducted over an 18-month period.

Results A total of 26 patients met criteria; 17 reported symptoms entered against the variable values of the CTCAE v5. Common symptoms included xerostomia (grade 1/2), altered taste (grades 1/2), mucositis (grades 1/3), thick saliva (grades 1/2), and skin reactions (grade 2/3). Hospital admission was required for 80.8% of patients, 69.3% required a feeding tube, 100% of patients required oral supplements, and 61.6% needed intravenous (IV) hydration. Treatments breaks were limited to two patients.

Conclusion This study highlights the complex symptom experience of patients treated with CRT for HNC and their need for supportive care, highlighting the contribution from all members of the multidisciplinary team.

Background

Head and neck cancer (HNC) is the 7th most common cancer in Australia, with 5,212 new cases projected, and the predicted mortality of 1,202 ranked at 15 out of all cancers for 2019[1]. Approximately 60% of patients are diagnosed with advanced disease and the incidence is twice for men as for women[2]. Concurrent chemoradiation therapy (CRT) has become the standard of care for patients with head and neck squamous cell carcinomas (HNSCC) due to the sensitising effect of some chemotherapy agents[3,4]. This treatment regimen results in organ preservation with the hope of sparing function, thus reducing issues with the patient's ability to talk and swallow[5].

However, the synergistic effects of concurrent CRT have been widely documented in the literature and have been found to have a negative impact on patients' quality of life (QoL), requiring local and systemic interventions[6]. Recent technology, such as transoral robotic surgery (TORS), has emerged as an alternative to non-surgical CRT regimens due to its comparable tumour control and functional advantages[7]; however, it is not currently widespread in its usage at the study centre.

Over the past several decades the epidemiology of HNC has changed quite significantly, with human papilloma virus (HPV)-mediated disease common in the oropharynx, and to a lesser extent, the oral cavity, larynx and hypopharynx, as determined histologically by the p16+ve status[8–10]. Smoking- and alcohol-related HNSCC is reducing in Australia, while the HPV-related HNSCC is increasing[11]. Compared to patients with p16–ve disease, patients with HPV-related HNSCC have been found to have improved locoregional and overall survival rates[12]. However, irrespective of the epidemiological nature of HNSCC, the

toxicities experienced during CRT for oropharyngeal cancer were similar for both cohorts[13].

Significant treatment-related toxicities occur throughout CRT, with the most severe side effects occurring towards the end of the course of treatment[4]. These patients are at high risk for poor outcomes and may experience a range of mild (grade 1) to severe (grade 3) toxicities over the course of treatment and beyond[14]. Focal tissue injury may include radiodermatitis, mucositis and pain, as well as xerostomia, dysgeusia, thickened oral secretions, odynophagia and dysphagia, and may negatively impact weight, wellbeing and QoL[14,15]. Systemic effects include fatigue, nausea, insomnia and weight loss[6], contributing to dehydration, vomiting and constipation. Constipation can be caused by opioid and/or antiemetic use to optimise pain and nausea management[14]. Cachexia during cancer is characterised by systemic inflammation, negative protein and energy balance, with an involuntary loss of lean body mass[16]. The cachexia syndrome may be reinforced by systemic inflammation induced by oral mucositis and reduced energy intake as a result of acute toxicities leading to reduced swallowing capacity[6,17]. The impact of side effects such as poor oral intake, poor nutritional status, poor QoL and psychosocial deficits often result in hospitalisation[18].

This cohort of patients requires proactive, specialised care from the multidisciplinary team consisting of radiation oncologists, radiation therapists, radiation oncology nurses, dietitians, speech pathologists, social workers, physiotherapists and occupational therapists[19]. HNC patients need support to manage the treatment and its toxicities, to minimise psychosocial impacts and, where possible, to prevent hospitalisations and possible treatment breaks. Within the study centre, it is standard practice that all patients with HNC undergoing RT or CRT are cared for by a primary radiation oncology nurse who works closely with the specialist radiation oncologist. Furthermore, this cohort of patients also receives routine and regular intervention from the dietitian and speech pathologist in order to minimise the effects of treatment-related toxicities on nutritional and functional status. Patients are referred to other allied heath staff as indicated.

Aims of the study

The aims of this Australian study are to explore (1) the range of symptoms documented by the multidisciplinary team and reported by patients; and (2) the documented supportive care provided by the multidisciplinary team during CRT for HNC in a tertiary radiation oncology department in Brisbane, Australia.

Methodology

Design and participants

The study design is a retrospective chart review (RCR) of all patients with HNC treated with concurrent CRT at Radiation Oncology Princess Alexandra Hospital Raymond Terrace (ROPART) Centre over an 18-month period. Patients with HNC that did not have concurrent CRT (ie. radiotherapy alone, or primary surgery followed by post-operative CRT) were excluded from the study.

Procedure

Demographic information was obtained from MOSAIQ[20]. Patients who fit the inclusion criteria had their baseline data retrieved from a department-initiated Self-Assessment Questionnaire (SAQ). Two specific criteria of importance were (1) pain measured on a Likert scale where 0=no pain, and 10=highest pain, and (2) distress, measured on the Distress Thermometer (DT) (0=no distress, and 10=highest distress)[21]. Baseline data from the SAQ was collected on the radiation therapy (RT) planning day, approximately 2–3 weeks before starting RT.

On-treatment documented side effects were retrieved from two electronic medical records, MOSAIQ and the integrated electronic medical record (ieMR). Documented symptoms from MOSAIQ/ieMR were aligned against the Common Toxicity Criteria – Adverse Events (CTCAE) v5[22]. Toxicity severity was tabulated based on the documented descriptors and impact on functional status reported by the patient or observed by the clinicians – the radiation oncologists, radiation oncology nurses and allied health staff. Toxicity grades for the CTCAE v5 reports symptoms ranging from 0–4 (0=no symptom; 4=worst symptom). The most severe level of documented symptom in MOSAIQ/ieMR (regardless of the time point during treatment) was recorded for the RCR. The corresponding author [PR] undertook initial review of the electronic medical records, and compiled an initial database of recorded outcomes and interventions that was then provided to JF and EK. These associate investigators, in turn, interrogated the records from their specialist perspectives, and challenges were discussed between all three authors until consensus was reached. The fourth author, BB, then became an oversight reviewer, lending her expertise to the final reporting and writing of the manuscript.

Data were recorded and analysed using the Statistical Package for the Social Sciences (SPSS)[23]. The Metro South Human Research Ethics Committee (Brisbane, Australia) assessed this study and deemed it "negligible risk", thus a waiver for consent was granted. All care was taken with maintaining patient anonymity and confidentiality throughout the study process.

Data analysis

Demographic and medical data were recorded as dichotomous variables or in groups and reported as frequencies (Table 1). The documented symptoms were analysed and entered into the database against the values of the CTCAE v5 and, if no documentation was found, they were reported as 'not reported' or 'not documented'. Due to the number of different diagnostic sites (15 for only 26 patients), the sites of cancer treated were therefore collapsed into three broad categories – hypopharynx, oral cavity, and oropharynx to allow for more meaningful analysis[24]. The variable 'chemotype' was used to

describe the concurrent use of intravenous (IV) low dose (LD) cisplatin (a platinum-based antineoplastic), IV high dose (HD) cisplatin, or IV cetuximab (an epidermal growth factor inhibitor). Correlations between variables were calculated using the non-parametric test Spearman's *rho* and was considered significant at the 0.05 level (2-tailed). Associations between demographic and outcome variables were assessed using the non-parametric Mann-Whitney *U* and Kruskall-Wallis *H* tests. Interventions, including all supportive care provided to the patient by medical, nursing and the allied health team, were reported as frequencies, including admission to hospital.

Results

A total of 26 patients fulfilled the inclusion criteria for this study over an 18-month period. The majority of patients was diagnosed with oropharyngeal cancer and were men, with only four women receiving concurrent CRT during the study timeframe, consistent with other reports[1] (Table 1). Patient-reported baseline data in the SAQ revealed that many participants (61.4%) experienced some degree of distress and/or pain prior to commencement of treatment (Table 1).

Table 1. Demographic data

Variable	Value	n	%
Gender	Male Female	22 4	84.6 15.4
Age	<60 60+	12 14	46.2 53.8
Area treated	Oropharynx Oral cavity Hypopharynx	14 6 6	53.8 23.1 23.1
Tumour type	Squamous cell carcinoma Carcinoma Merkel Cell	24 1 1	92.3 3.8 3.8
P16 status	Yes No Oropharynx p16+ve Hypopharynx p16+ve Oral cavity p16+ve Male p16+ve Female p16+ve	13 13 11 1 1 11/13 2/13	50 50 42.4 3.8 3.8 84.6 15.3
Chemotype	Low dose Cisplatin High dose Cisplatin Cetuximab	5 14 7	19.2 53.8 26.9
Gray	<70 >70	7 19	26.9 73.1
Fractions	< 30 >30	7 19	26.9 73.1
Table 1a: Baseline Measurements: Self-Assessment Questionnaire (SAQ) and Distress Thermometer (DT) (2-3 weeks pre commencement of radiation therapy)			
Pain Likert scale 1 - 10	No / Not documented 14 = 53.9%	Between 1-3 5 = 19.2%	Between 4-7 7 = 26.9%
Distress Thermometer Likert scale 1 - 10	No distress/not documented 10 = 38.4%	Between 1 – 3 9 = 34.6%	Between 4-8 7 = 26.8%

Symptoms

Following review of the electronic medical records, 17 symptoms were documented that included altered nutrition and hydration, focal symptoms and generalised systemic symptoms. The CTCAE v5 definitions of instrumental and self-care activities of daily living (ADL) that are used to describe various levels of criteria are described in Figure 1.

Common toxicity criteria adverse events: definition of activities of daily living (ADL)

Instrumental ADL refers to preparing meals, shopping for groceries or clothes, using the telephone, managing money, etc.

Self-care ADL refers to bathing, dressing and undressing, feeding self, using the toilet, taking medications, and not bedridden.

Figure 1. Definition of ADL

Altered nutrition and hydration

Xerostomia was documented for all patients, with 34.6% (9) of patients experiencing moderate symptoms (grade 2) with impact on oral intake (Table 2). Dysgeusia was reported by all but one patient, with 50% (13) experiencing grade 2 taste alterations affecting oral intake. During the treatment, 69.2% (18) reported mild to moderate treatment-related pain (grades 1,2), with 26.9% (7) being documented with severe pain (grade 3). Moderate (grade 2) mucositis was reported by 42.3% (11) of patients, and severe (grade 3) mucositis was documented for 30.8% (8), who required a modified diet. Ropey, thick saliva, with changes in diet and secretion-induced symptoms which limited function was experienced by 38.5% (10) of patients. Fifty percent (50%) (13) reported altered eating patterns (grade 2) due to dysphagia, and two patients (7.7%) had severely altered eating/swallowing also due to dysphagia (grade 3).

Slightly more than half (53.8%, 14) were reported as experiencing anorexia associated with weight loss and malnutrition, requiring tube feeding (grade 3), with 69.2% (18) requiring tube feeding in total. Nearly three-quarters of patients (73.1%, 19) were documented as having oral candidiasis. Odynophagia was reported in all patients, with 69.2% (18) experiencing moderate to severe symptoms (grades 2, 3) (Table 2); 23% (6) of these patients were documented with a limited ability to swallow. Weight loss was experienced by the majority of patients, with 57.7% (15) losing 5–10% of their baseline weight (grade 1), and 15.4% (4) losing 10–20% (grade 2) (Table 2). A Kruskall-Wallis *H* test showed that there was a statistically significant difference in weight loss between the three IV chemotherapy regimens: 7.101 (df=2), p=.030,

Table 2. Documented symptom severity

Symptoms	CTCAE v5 grades	n (n=26)	%
Xerostomia	G0: No/not reported/documented	0	0
	G1: Symptomatic without sig diet alteration	17	65.4
	G2: Moderate symptoms; oral intake alterations	9	34.6
Dysgeusia	G0: No/not reported/documented	1	3.8
	G1: Altered taste, no change in diet	12	46.2
	G2: Altered taste, change in diet, noxious or unpleasant taste, loss of taste	13	50.0
Pain	G0: No/not reported/documented	1	3.8
	G1: Mild pain	3	11.5
	G2: Moderate pain; non-narcotics initiated; topical analgesics initiated	15	57.7
	G3: Severe pain, altered eating/swallowing; narcotics initiated; parenteral support	7	26.9
Radiation dermatitis	G1: Faint erythema or dry desquamation	7	26.9
	G2: Mod/brisk erythema; patchy moist desquamation-skin folds/creases; mod oedema	10	38.5
	G3: Moist desquamation in area other than skin folds; bleeding induced/minor trauma	9	34.6
Oral mucositis	G0: No/not reported/not documented	2	7.7
	G1: Asymptomatic or mild symptoms; interventions not indicated	5	19.2
	G2: Moderate pain or ulcer; not interfere with oral intake; modified diet	11	42.3
	G3: Severe pain interfering with oral intake	8	30.8
Rash	G0: No/not reported/not documented/N/A	18	69.2
	G1: Maculo/papular eruption <10%with/out associated symptoms	3	11.5
	G2: Maculo/papular eruption 10–30% BSA with/out severe symptoms limiting instrumental ADL; psychosocial impact	3	11.5
	G3: Macules/papules >30%, BSA modes/limiting self-care ADL	2	7.7
Salivary duct inflammation	G0: No/not reported/documented	4	15.4
	G1: Slightly thickened saliva, slightly altered taste	12	46.2
	G2: Ropey sticky saliva; diet alter. secretion-induced symptoms; limit instrument ADL	10	38.5
Thrush	G0: No/not documented/not reported	7	26.9
	G1: Oral intervention indicated e.g. antifungal	19	73.1
Insomnia	G0: No problems sleeping/not documented/not reported	8	30.8
	G1: Mild difficulty falling asleep, staying asleep, waking up early	10	38.5
	G2: Moderate difficulty falling asleep, staying asleep, waking up early	8	30.8
Hoarseness	G0: No/not reported/not documented/laryngectomy (1 patient), 1 missing	6	26.7
	G1: Mild or intermittent voice change; fully understandable; self-resolves	10	38.5
	G2: Moderate/persistent voice changes, require occ repetition; understand on phone	7	26.9
	G3: Severe voice changes including predominantly whispered speech	3	1.5
Fatigue	G0: No/not reported/not documented	2	7.7
	G1: Fatigue, relieved by rest	13	50.0
	G2: Fatigue not relieved by rest, limiting instrumental ADL	9	34.6
	G3: Fatigue not relieved by rest; limiting self-care ADL	2	7.7
Odynophagia	G1: Mild pain	8	30.8
	G2: Moderate pain; limiting instrumental ADL	12	46.2
	G3: Severe pain, limiting self-care ADL, limiting ability to swallow	6	23.0
Dysphagia	G0: No symptoms/not documented/reported	6	23.1
	G1: Symptomatic; able to eat regular diet	5	19.2
	G2: Symptomatic/altered eating/swallowing	13	50.0
	G3: Severely altered eating/swallowing; TPN, tube feeding, hospitalisation	2	7.7
Nausea	G0: No/not reported/not documented	2	7.7
	G1: Loss of appetite without loss of eating habits	7	26.9
	G2: Oral intake decreased without sig weight loss, dehydration, malnutrition	6	23.1
	G3: Inadequate oral calorific or fluid intake; tube feeding, TPN or hospitalisation	10	38.5
Anorexia	G0: No/not reported/not documented	2	7.7
	G1: Loss of appetite without alteration in eating habits	1	3.8
	G2: Oral intake altered without significant weight loss/malnutrition; oral supplements	9	34.6
	G3: Associated with weight loss/malnutrition; tube feeding/TPN indicated	14	53.8
Constipation	G0: No/not reported/documented	4	15.4
	G1: Occ/intermittent symptoms, occ laxatives, diet, modifications, enemas	19	73.1
	G2: Occ/intermittent symptoms; reg laxatives/enemas, ↓instrumental ADL	3	11.5
Weight loss	G0: Maintained/not reported/not documented	7	26.9
	G1: 5–10% from baseline	15	57.7
	G2: 10–20% from baseline	4	15.4

with a mean rank score of 6.30 for those receiving CRT with LD cisplatin, 12.79 for HD cisplatin and 15.17 for cetuximab (Table 3).

Generalised symptoms

Half of the patients (13) had documented mild fatigue relieved by rest (grade 1); however, 34.6% (9) reported fatigue not relieved by rest, limiting function (grade 2), and 7.7% (2) experienced fatigue not relieved by rest, limiting self-care ADL (grade 3). Grade 1 constipation was reported by 73.1% (19) of patients requiring either occasional laxatives, diet modifications, increased fluid intake, or enemas, while 11.5% (3) reported grade 2 symptoms requiring regular laxatives or enemas. A proportion of patients (38.5%) (10) reported mild difficulty falling asleep (grade 1), while 30.8% (8) experienced moderate difficulty either falling asleep, staying asleep, or waking up early (grade 2) (Table 2). Vocal hoarseness was documented for more than three quarters of the patients (20), with levels from mild to moderate (17) with persistent voice changes, requiring occasional repetition, and grade 3 (11.5%) (3) with more severe voice changes including mainly whispered speech (Table 2).

Skin reactions

All patients reported varying degrees of radiation-induced skin reactions. Faint erythema or dry desquamation was reported for 26.9% (7) (grade 1), 38.5% (10) were documented as grade 2 with a moderate to brisk erythema, patchy, moist desquamation mostly confined to skin folds and creases, and 34.6% (9) were documented with moist desquamation in areas other than skin folds and creases (grade 3) (Table 2). Those patients who received IV cetuximab (26.9%) (7) plus one patient who received HD cisplatin were documented as having a rash. Maculo/popular rash grade 1 (eruption to <10% body surface area (BSA) with/out associated symptoms) was reported for 11.5% (3) of patients, grade 2 (to 10–30% BSA with/out severe symptoms limiting function with psychosocial impact) was documented for 11.5% (3), and grade 3, limiting self-care ADL, was documented for 7.7% (2) (Table 2).

Interventions

To manage the documented side effects, the multidisciplinary team documented 12 documented interventions which were scored according to the various levels of the intervention or as dichotomous variables. Supportive care was provided by medical, nursing and allied health professionals.

Medical/nursing interventions

Admission to hospital was required for 80.8% (21) of patients during the course of the radiotherapy, with 15.4% (4) admitted routinely following chemotherapy, and 65.4% (17) admitted for emergent, unplanned issues and supportive care (Table 3). IV hydration was required by 61.6% (16) of patients and was either given in the radiation oncology department or on admission to the ward. A range of narcotic analgesia was required for 88.3% (23) of patients during their treatment (Table 3), and topical oral analgesia was utilised by 80.8% (21), with 7.7% (2) not tolerating it due to taste dysfunction. Patients with candidiasis 73.1% (19) required a topical, oral antifungal medication. The use of departmental daily humidification to improve the comfort of the oral mucosa and support secretion management was reported by 65.4% (17) of patients, one patient disliked it, and two patients used humidification at home (Table 3).

All (100%) patients had documented adherence to routine oral cares in the form of regular salt and sodium bicarbonate mouthwashes. Oral antiemetics were prescribed for 73.1% (19) of patients in addition to the standard care IV antiemetic drugs given during their chemotherapy, most commonly in the HD cisplatin group. All but five patients were documented as applying a skin moisturiser over the treatment area during the course of treatment (Table 3) with sorbolene and aqueous cream (without the skin irritant sodium lauryl sulphate) as is departmental advice, with two patients using 'Triple Treat', a combination of a hydrogel gel, topical 2% lignocaine and paraffin to provide local pain relief and comfort. One patient reported using Betnovate, a corticosteroid. Nurse-applied dressings to the treatment site were documented for 67.7% (15) of patients. Five patients (19.2%) required IV antibiotics during the course of treatment for fever, respiratory tract infection and an infected PEG insertion area (Table 3).

Allied health interventions

All patients received intervention from a dietitian and speech pathologist, usually in joint sessions on a regular basis. These health professionals routinely addressed concerns with swallowing, nutrition management and oral cares. Oral nutritional supplementation was required for 100% of patients following dietetic assessment. The need for a nasogastric tube (NGT) was required for 46.1% (12) of patients, and a gastrostomy tube was indicated for 23.1% (6) of patients (Table 3).

The social worker provided intervention to 76.9% (20) of patients, 61.8% of patients were seen by the physiotherapist (16), and 42.3% (11) by the occupational therapist.

Relationships between variables

There were several relationships demonstrated between various patient demographics/treatment factors and documented side effects using the non-parametric Mann-Whitney *U* and the Kruskal-Wallis *H* tests (Table 4). IV cetuximab was significantly associated with maculo/papular skin rash (p=.001) and significant weight loss (p=.030). Low dose weekly IV cisplatin was significantly associated with greater radiation skin reaction (p=.012), as were doses of radiation <70Gy (p=.011). This may be due to patients on the weekly protocol being less medically fit than those on the high-dose 3-weekly regime[25]. CRT to the oropharynx resulted in significant associations with dysgeusia (p=.007), sleep disturbance (p=.045) and hoarseness (p=.022). Salivary duct inflammation,

Table 3. Documented outcomes

Outcome	Response	n	%
Admission	No LD cisplatin x 2 HD cisplatin x 1 Cetuximab x 1	5	19.2
	Yes post chemo LD cisplatin x 1 HD cisplatin x 3 Cetuximab x 0	4	15.4
	Yes supportive care LD cisplatin x 2 HD cisplatin x 9 Cetuximab x 6	17	65.4
Humidifier	Yes: in department	17	65.4
	No	6	23.1
	Didn't like it	1	3.8
	Used at home	2	7.7
Social work	Yes	20	76.9
	No	6	23.1
Dietitian	Yes	26	100
	No	0	
Speech pathology	Yes	26	100
	No	0	
Physiotherapist	Yes	16	61.8
	No	10	38.5
Occupational therapist	Yes	11	42.3
	No	15	57.7
Analgesia	Not reported	1	3.8
	Paracetamol	2	7.7
	Opiates	23	88.3
Feeding tube	No	8	30.8
	Gastrostomy tube	6	23.1
	Nasogastric tube	12	46.1
Food supplements	Yes	26	100
Intravenous hydration in department	Yes	16	61.6
	No	10	38.5
Xylocaine Viscous	Yes	21	80.8
	No	3	11.5
	Didn't like it	2	7.7
Salt/Sodi bicarb mouthwashes	Yes	26	100
Antiemetics	No/not reported/documented	4	26.9
	Yes	19	73.1
Dressings	No/not reported/documented	11	32.3
	Yes	15	67.7
Moisturiser	Sorbolene/aqueous/other	21	76.9
	Betnovate	1	3.8
	'Triple Treat'	2	7.7
	Not reported/documented	3	11.5
Antibiotics	No/not reported	21	80.8
	Yes	5	19.2

resulting in thick, ropey saliva, was associated with >34 daily fractions (p=.032); higher levels of odynophagia was associated with p16+ve status (p=.009). Moderate correlations were reported for salivary duct inflammation and sleep (r=.620), mucositis and fatigue (r=.609); pain and odynophagia (r=.585), thrush and nausea (r=-.506); hoarseness and dysphagia (r=.491), nausea and constipation (r=.486); pain and weight loss (r=.478), and fatigue with odynophagia (r=.458) (Table 5).

Discussion

The HNC patients undergoing concurrent CRT in our study experienced a range of radiation and chemotherapy-induced toxicities, worsened by the synergistic effects of the two treatment modalities. The current study and others have found these treatment-induced toxicities can be severe, and many of them are interrelated, possibly affecting wellbeing and QoL[2,17,26]. This is in line with a study by Zandberg et al.[27] that found patients receiving CRT compared to those receiving RT alone reported higher numbers of gastrostomy tube placement, dysphagia and weight loss.

The symptoms that were documented in the patients' electronic medical records in this study were consistent with those reported in the literature[15,27,28]. Patients who received IV cetuximab had a higher weight loss score in comparison to those receiving LD cisplatin and HD cisplatin. A study by Magrini et al.[29] found that at the end of CRT the weight loss associated with IV cetuximab (6%) was minimally less than in patients receiving cisplatin (8%). However, these authors also reported the cetuximab group requiring more nutritional support during treatment.

It has been shown that deficits in nutrition and hydration, if severe, may lead to hospitalisation[30,31] and the need for alternative feeding[29,32]. Intervention by the dietitian and speech pathologist was constant in relation to assessment, nutritional supplementation and tube feeding. The weight loss that was experienced by nearly three-quarters of the patients was consistent with other studies[33,34], and the need for a feeding tube (69.2%) was consistent with that reported elsewhere[32].

Patients with HNC may have higher levels of cancer-related pain compared with other cancers, requiring more intensive pain management in order to control pain and maintain daily functioning[35]. Over a quarter of patients in the present study self-reported moderate levels of cancer-related pain and distress before treatment commenced. This necessitated early intervention on treatment planning day by the primary nurse with referrals to medical and allied health staff. During the course of treatment, a large number of our patients also reported mild to moderate treatment-related pain, and just over a quarter of patients were documented with severe pain, nearly all requiring opioid narcotics. Patients undergoing CRT protocols in particular may experience exacerbated toxicities including painful mucositis, often resulting in reduced QoL, poor oral

Table 4. Relationships between variables

Characteristic	Symptom	Values	n	Mean rank	p value
Chemotype [Kruskall-Wallis *H* test]	Rash	LD cisplatin	5	9.50	
		HD cisplatin	14	10.25	
		Cetuximab	7	22.86	.001
	Skin grade	LD cisplatin	5	18.20	.012
		HD cisplatin	14	9.61	
		Cetuximab	7	17.93	
	% weight loss	LD cisplatin	5	6.30	
		HD cisplatin	12	12.79	
		Cetuximab	6	15.17	.030
Area treated [Kruskall-Wallis *H* test]	Taste	Oropharynx	14	16.88	.007
		Oral cavity	4	9.58	
		Hypopharynx	6	8.50	
	Sleep	Oropharynx	14	16.71	.045
		Oral cavity	6	10.50	
		Hypopharynx	6	9.00	
	Hoarseness	Oropharynx	14	10.25	
		Oral cavity	6	13.33	
		Hypopharynx	5	20.30	.022
Fractions [Mann-Whitney *U* test]	Xerostomia	≤30	7	9.00	
		>34	19	15.16	.027
	Salivary duct	≤30	7	8.64	
		>34	19	15.29	.032
	Dysgeusia	≤30	7	6.57	
		>34	19	16.05	.001
p16 status [Mann-Whitney *U* test]	Xerostomia	Yes	13	16.00	.043
		No	13	11.00	
	Pain	Yes	13	17.08	.007
		No	13	9.92	
	Odynophagia	Yes	13	17.12	.009
		No	13	9.88	
Dose of radiation (Gy)	Skin grade	<70Gy	7	19.43	.011
		=/>70Gy	19	11.32	

intake, weight loss and, occasionally, treatment interruptions[36]. This highlights the importance for health professionals to be proactive in the pain management of these patients. Clinical recommendations for managing pain in HNC patients suggest that odynophagia be treated as an incidental pain, but that more complex pain is a result of the multiple mechanisms involving the gastrointestinal tract secondary to chemotherapy and RT, requiring both local and systemic pain management strategies[37]. Our study also showed significantly greater xerostomia, pain and odynophagia in those patients who were p16+ve (Table 4).

All patients reported varying degrees of radiation-induced skin reactions, and although current radiotherapy technologies are more skin-sparing than in the past[38,39], the skin is often adjacent to the target structures and, as such, some level of radiodermatitis is expected[15]. For some patients there may be the overlaying of the EGFR inhibitor acne-like rash typical of cetuximab with radiation dermatitis in the irradiated fields. Authors have assessed enhanced toxicity with cetuximab and found a high rate of in-field grade >3 cutaneous toxicities, and that severe mucosal and skin toxicities appeared earlier than expected, with moist desquamation from the 3rd and 4th week of treatment[40].

Studies have found the impact of mucositis exacerbates systemic side effects such as fatigue and nausea[17]. Nausea may be a consequence of chemotherapy and is generally relieved by antiemetics, but these medications need to be carefully managed so as not to cause constipation in this patient cohort which may further exacerbate nausea and nutritional deficits[41]. Moderate correlations were seen for salivary duct inflammation and sleep

Table 5. Correlations between outcome variables

Variables	n	Spearman's *rho*	Sig (2-tailed) p
Salivary duct inflammation Sleep	26	.620**	.001
Mucositis Fatigue	26	.609**	.001
Pain Mucositis	26	.600**	.001
Pain Odynophagia	26	.585**	.002
Thrush Nausea	25	-.506**	.010
Hoarseness Dysphagia	25	.491*	.013
Nausea Constipation	26	.486*	.014
Pain Weight loss	23	.478*	.021
Fatigue Odynophagia	26	.458	.019
Salivary duct inflammation Thrush	26	.428*	.029
Xerostomia Taste	23	.409*	.038
Nausea Anorexia	25	.400*	.048
Xerostomia Odynophagia	26	.385*	.046

*Correlation is significant at the 0.05 level (2-tailed)

** Correlation significant at the 0.01 level (2-tailed)

as reported by others[42]. Other study participants reported waking with a dry mouth, drinking large quantities of liquids during the evening and night, necessitating regular nocturnal micturition, or a sensation of choking on thick secretions, causing interruptions to sleep[43,44]. Mucositis and fatigue were also described in a review of symptom clusters for HNC patients receiving CRT, where these symptoms were found to be components of the head and neck cluster that also included radiodermatitis, dysphagia, xerostomia, pain and taste disturbance[15]. Candidiasis superimposed on mucositis may occur if oral hygiene to the oral cavity is not managed appropriately; this may require a topical antifungal therapy[45].

QoL for this type of patient cohort has been reported to be better in well-nourished patients than in malnourished patients, underlining the importance of nutritional interventions during CRT for HNC[46,47]. Dysphagia is a common side effect of HNC and may predate the treatment. Unfortunately, it can be associated with nutritional deficiency and weight loss, and is often experienced with mucositis, pain, xerostomia, hoarseness and loss of taste, amongst others[48,49]. A qualitative study sought to explore the experience of HNC from patients' perspectives and found that patients reported challenges with salivary changes and the impact it had on sleep, which in turn disturbed the patients' emotional equilibrium[50].

In the current study, unplanned hospitalisations were higher for patients receiving HD cisplatin and cetuximab, possibly due to more severe acute toxicity profiles compared with those patients receiving LD cisplatin. A study by Terzo et al.[51] described a weekly nurse practitioner assessment for a similar cohort that resulted in 27% of unplanned admission. A further study by Moore et al.[52] reported 36% of unplanned admissions for those with high comorbidity scores. Muzumber et al.[53] retrospectively reported a 25% unplanned admission rate, with unscheduled breaks (>2 days) occurring in 46 (31%) of patients due to toxicity, and five for social reasons; a high proportion of patients in their study did not complete treatment. None of the studies reviewed reported a nursing model of care or allied health intervention.

The study by Pryor et al.[54] reported that four of 13 (30.7%) patients required significant treatment breaks during CRT with cetuximab, with six of the 13 (46.2%) patients admitted during treatment. Of the seven patients in our study who received IV cetuximab one patient was admitted to hospital for a gastrostomy tube change with a break of 3 days as the hospital was some distance to the radiation treatment centre, and a second patient missed 2 days after admission to hospital with distressing mucositis and skin reaction. Authors have found that treatment breaks for this type of patient cohort may have a negative effect on survival outcome[55,56]. Therefore, preventing treatment breaks due to side effects and deterioration could be the most important result of appropriate intervention by the multidisciplinary team.

In the current study several conditions related to the study site need to be outlined – the availability of a primary nurse for daily or other assessment as required by each patient, weekly team meetings with the radiation oncologist, primary nurse and allied health staff, the intervention for all HNC patients by a dietitian and speech pathologist, and communication between advanced practice nurses of both treatment modalities underpins good communication about these patients, resulting in close surveillance by the team. This may result in timely admission for emergent problems resulting in few treatment breaks.

Limitations of the study

The main limitation of this study is in its retrospective design, limiting data collected to that documented in the electronic medical records. Also, data analysis was limited by the small number of patients that fulfilled the study criteria during the timeframe of the chart audit. Another limitation of this study is that the DT was assessed at one time point only. Future standard care and research should consider routine screening for distress as recommended by the National Comprehensive Cancer

Network (NCCN), especially during and at the end of treatment, which is currently being implemented at the study centre.

Implications for nursing

The retrospective chart review provides an important local perspective of actual patient outcomes in response to the treatment and interventions provided. It also demonstrates where there may be gaps in care. Supporting and encouraging patients to maintain their oral hygiene practices and monitoring their oral intake are possibly the two most important interventions for this patient cohort. This is linked with patient comfort, including both local and systemic analgesia, which requires close observation and monitoring. Many of the toxicities experienced by this patient cohort are interrelated, thereby highlighting the need for holistic patient management by radiation oncology nurses.

Conclusion

This RCR has highlighted both the multifaceted and complex range of side effects documented for patients undergoing concurrent CRT for HNC, and the supportive care provided by the multidisciplinary team. Despite regular monitoring and interventions by the multidisciplinary team there was still a relatively high number of admissions. There were, however, minimal treatment breaks as previously noted. The optimal management, therefore, of these patients requires a multidisciplinary team approach that focuses on the morbidities and other factors that may impact treatment interruptions to provide a range of support for the best long-term outcomes for each patient.

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