The Australian Journal of Cancer Nursing

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In this issue

Cancer Nurses Society of Australia

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Dr. Linda Watson has been an oncology nurse in Calgary, Alberta, Canada for over 25 years. She has held a variety of nursing and inter-professional leadership roles within the Cancer Control Alberta (CCA) provincial program and is currently the provincial Lead for Person Centred Care Integration within Alberta's provincial cancer care program. Dr. Watson completed her doctoral research in 2014, where she explored the family's experience of living with incurable but treatable cancer.

Dr. Watson holds an adjunct professor position with the Faculty of Nursing at the University of Calgary, but her passion for improving the patient experience has kept her committed to her full time position as a transformational leader within the Alberta cancer system. Committed to enhancing the person centredness of the cancer care system she has worked closely with the Canadian Partnership Against Cancer (CPAC) and the Alberta Cancer Foundation (ACF) to develop new processes, systems, and programs to enhance clinical capacity to deliver tailored, individualised care to cancer patients in the ambulatory cancer setting. These include using Patient Reported Outcomes (PROs) to improve patient experience, the implementation and evaluation of a provincial cancer patient navigation program to improve the rural cancer patient's access to cancer care, and a provincial post-treatment transitions program that aims to improve the transition between the cancer program and primary care.

Dr. Watson is also currently the President of the Canadian Association of Nurses in Oncology (CANO), providing national leadership to the specialty area of oncology nursing across Canada.

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The Australian Journal of Cancer Nursing

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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

All correspondence relating to the journal should be directed to the editors. Guidelines for contributors to the journal can also be obtained from the editors. The *AJCN* is published twice a year.

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Editorial

Celebrating 21 years of the AJCN

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This issue of the *Australian Journal of Cancer Nurses* celebrates the 21st birthday of the Cancer Nurses Society of Australia (CNSA) and of the journal. So, happy birthday to us.

Volume #1 Edition #1 was published in September 1998, heralding the official launch of the CNSA in November 1998. The three articles in that inaugural volume reflected on the key professional and practice issues of the day:

- Advanced oncology nursing practice: An essential integration of clinical practice, education and the professional body by Lillian Daly;
- Collaboration between clinicians and academics: Achieving outcomes in oncology and palliative care nursing research (Lesley Wilkes, Kate White and Sally Tracy); and
- Factors influencing nurses' abilities to impact on cancer: Exploring graduates' perceptions (Gabrielle Prest).

Interestingly, the common theme inherent in that first volume — the value and importance of collaboration between nurses working in practice, education and research — has retained a place for discussion over the last 21 years. This theme is the mortar for the building blocks of excellence in cancer nursing practice, and the discussion has developed, influencing publications and practice as well as conversations at conferences and in tea rooms, and it remains as important today as it was 21 years ago.

The journal has grown and developed with the CNSA over its 21 years. Patsy Yates and Catherine Johnson took those initial leadership steps as the first Editors in September 1998, with only one edition a year initially published. Laurie Grealish joined the editorial team in 1999. The *AJCN* was initially published by Creative Logic, the PCO for CNSA, supported in part by a grant from Amgen. The journal publication later moved to Cambridge Media, where we have been supported to develop the journal publication further.

The journal took the — at the time — bold step to move to two editions a year in 2002.

In 2009, Tish Lancaster and Mei Krishnasamy took over as Editors. There had been difficulty in soliciting manuscripts in the previous two years, so a decision was made publish themed editions about a particular cancer or clinical issue, inviting clinical experts to provide overviews on the current state of play. This proved unsustainable, so the journal returned to proffered papers, with authors often being recruited at the annual congress. Mei Krishnasamy resigned at the end of 2011 and Moira Stephens, who had been a member of the Editorial Board, became Co-Editor in 2012.

The year 2018 saw the move to Scholar One — the electronic management system which has made an enormous difference to the editorial management and process — and thanks to Greg Paull and the team at Cambridge Media for their support and work with that.

This year — as we have come of age — we have, for the first time published as hard copy and electronic copy and appointed two new Associate Editors, as Tish and I say goodbye to the journal and move to pastures new.

We are pleased that the CNSA Board of Directors appointed Prof Karen Strickland and A/Prof Jacqueline Bloomfield as Associate Editors for 2019. They will assume the roles of Editors in 2020. Both Karen and Jacqueline bring a wealth of clinical, research, academic and publishing experience, addressing those themes highlighted in the very first edition.

On a personal note — I have loved and learned working with the CNSA, the editorial board, our generous growing team of reviewers and Tish, in particular.

Thank you, have fun and keep up the good fight for excellence in cancer care,

Moira Stephens

Factors affecting provision of care services for patients with cancer living in the rural area: an integrative review

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Abstract

This paper explored individual- and system-level factors affecting the provision of care services for rural patients. An integrated literature review across four databases identified 22 studies from six countries. A focus on health and wellbeing and the influence of rurality was explored. Findings indicate physical and functional health in rural cancer patients is lower in comparison with urban areas. Influencing factors were socio-economic status, age, income, health literacy, control and self-efficacy. Enhancing the strengths and education of caregivers and their inclusion in service decision-making are paramount for rural cancer patients and for the wellbeing of the caregivers. Disparities in rural areas need to be explored with longitudinal research to understand the clinical, social and cultural characteristics in relation to remoteness. The use of innovative technologies has been recommended as an option to enhance the health access and enable quality care provision across rural areas.

Knowledge translation

- The facilitation of access to innovative health care to balance the disparities of rural people (telehealth, online support groups, follow-up phone calls, enticement for specialist care in rural areas).
- A holistic approach with education and support provided to the family is particularly important for rural patients as the family is a key source of social, emotional and informational support over the journey.

Introduction

Geographic location can be considered as one of the significant disparity indicators among cancer patients[1,2] influencing access to appropriate professional and social support[3]. Research has highlighted that rurality is linked with higher level of morbidity and mortality in cancer patients[2]. Disparity in rural areas can be divided into two levels: individual and system. The key factors at the individual level are the level of education, health literacy, income of the person and family, personal attitudes, social norms[1], family responsibilities[4], age, race, ethnicity[5], as well as remoteness of the home environment. Factors related to system level can be lack of access to services, travel time and distance, insurance coverage, health care expenses and transportation[1,5].

Rural patients with cancer have lower access and usage of health care services due to the distances from health services[6] as well as fewer social and community support groups[1]. The level of care and support that cancer patients receive during the transition to survivorship is critical. Patients and their carers confront the reality of moving from a supportive system within a health service to management of the continuing treatment effects in the home environment[7,8]. Rural patients may be at higher risk of poor physical health outcomes, which can lead to mental health problems[9] such as higher levels of distress, anxiety and depression[2].

Although there has been increasing research regarding the needs of cancer patients (health care, community, social care needs), there has been little focus on the care needs of patients in rural areas[2]. The number of rural patients is under-examined in the research and there has been limited research about their care, emotional and psychological health, and wellbeing[10]. In addition, there is a risk of generalisation from research exploring rural persons with cancer as rural characteristics and culture differ greatly[6,11]. Furthermore, most of the research explores patients' experience, with little exploration of the experience of the carer[12].

The aim of this study was to:

1. Explore the most common research measurement for assessing care needs (for example, health care, community and social care) of rural cancer patients.
2. Explore the factors affecting provision of care services for patients with cancer living in the rural area.

Design

An integrative review framework was used to investigate the influencing factors to care for rural patients with cancer. An integrative review includes a diverse range of papers to provide a deep understanding of the health care issue. Hence, an integrative review can be beneficial in providing sound information which results in theoretical knowledge as well as facilitating translation of research to practice. However, an integrative review can be criticised for the possibility of bias, particularly in the analysis section, which can be resolved and/or strengthened by including analytical/advanced quantitative/qualitative analysis techniques[13]. An integrative review framework by Whittemore and Knafl[13] was used, which included five stages: problem identification, literature search, data evaluation, data analysis and presentation.

Problem identification

This review used PIO framework (population, interest and outcome) for structuring the research question. The population included cancer patients, and carer/cancer caregivers; the interest was rural; and the outcomes were the provision of care services, including health care and community support services received. Question formulation occurred through regular meeting of the authors and consensus achieved two key questions:

1. What are the common research measurements for assessing care needs (for example, health care, community and social care) of rural cancer patients?
2. What are the individual- and system-level factors (facilitators and barriers) affecting provision of care services for patients with cancer living in rural areas?

Literature search

The following inclusion criteria were considered for this systematic literature review: inclusion of both quantitative and qualitative studies to explore both how the measure of care needs was completed but also the context around rural patients' needs during cancer. The time period of 2006–2018 was used as there has been an increasing amount of research in rural areas during the past decade. We included articles that were with either patients or their carers, peer-reviewed, written in English, and that described a measure for assessing the care needs of patients/carers of rural cancer patients. Papers were excluded if they did not identify care needs assessment associated with cancer, or only a small part of the paper was related to care needs assessment; the main focus was on health and wellbeing outcomes of patients/carers and not on the influencing factors and care needs; or they were not related to any cancer diseases, but focused on the diagnosis of cancer. We excluded papers that concentrated on prevention; focused on screening programs; focused on interventions to decrease disparities, a very small proportion of the paper was about rural populations, exploring the death and survivor trends; focused on the diagnosis and treatment variations; focused on diagnosis differences/stages and review papers/protocols/commentaries/books and those that were not conducted during 2006–2018.

There is a variety of different definitions regarding the rural areas based on different countries, which is mainly based on the population size/density, degree of urbanisation, and distance to the metropolitan areas (for example, areas outside the metropolitan areas that have a population of at least 1000 persons per square mile)[14]. Rurality can be defined by other social and cultural characteristics that are beyond only the sample and density of the population[15]. In the current literature review, international studies that were conducted in rural areas and identified their population as rural were included, regardless of their definition of rurality. There are diverse definitions for caregivers. For example, it can be defined as unpaid care and services, other social ties which can include a diverse ranges of individuals from other family members, or friends, and neighbours who are experiencing illness and/or chronic issues[16]. For the purpose of this study, the definition provided by Wright and Leahey was used[17], defining family/carer as individuals who are connected by strong emotional ties, with a high sense of belonging, and responsible for/a commitment to be involved in another's life.

Procedure and quality assessment

Four databases (CINAHL, Medline, PsychINFO, Informit Health — English language only) were searched using the following terms: "rural cancer patients" AND "carer" OR "cancer caregiver" AND "cancer" OR "oncology" AND "psychosocial resources" OR "health resources" AND "rural". After removal of duplications and irrelevant articles, 54 papers remained. A further 25 papers were added through the reference list and snowballing. A total of 79 papers remained for further investigation. The remaining full-text articles were reviewed by the three authors (EC, AS and VF) and a further 57 articles were excluded based on the inclusion and exclusion criteria (Figure 1). Data were extracted from the final 22 papers and entered into an Excel spreadsheet across the categories: author(s), year, country, study aim, research design, sample, care needs assessment, key findings, MMAT scores, and limitations of the research (Table 3).

For quality assessment, the Mixed Method Appraisal Tool (MMAT) was used[18] as the validated tool, which is considered appropriate for reviews including different types of studies (for example, quantitative, qualitative and mixed method). MMAT provides a quality assessment from 0, 25, 50, 75 and 100, the higher number indicates the higher quality of the paper[19].

Synthesis and analytical approach

Initial data were extracted from the primary papers; the main categories related to care needs and influencing factors to care for the patient and family as well as the key measurement tools for assessing the care needs of the patients in the context of the rural and remote areas. A content analysis was used including coding of the extracted data from the primary papers; creating categories by combining the relevant codes[20]. In addition, the measurements (including both quantitative and qualitative) used for assessing care needs of the rural patients and their carers were categorised.

Results

Descriptive findings and measurement tools for assessing care needs

A total of 22 papers were included in the review. The majority of studies were conducted in United States (n=13), followed by Australia (n=6), Scotland (n=1), Germany (n=1) and Uganda (n=1). Studies included a diverse range of cancers, including: breast cancer (n=6), colorectal cancer (n=3), lung cancer (n=1), malignant neoplasm (n=1) cancer and haematological cancers (n=1). A total of 10 studies did not focus on any specific cancer, rather explored a combination of cancers and/or advanced cancer as a general concept. The majority of studies were quantitative (n=14), followed by qualitative studies (n=5) and mixed-method studies (n=3). Studies measured patients' care needs and access to services. A number of recruitment methods were used, including mailed, paper-based, telephone-based or competed during treatment surveys[15]. Follow-up phone calls and incentives were reported to increase recruitment and retention[11,21]. Most studies' response rate was less than 50%, highlighting the difficulties of recruitment and retention of rural patients.

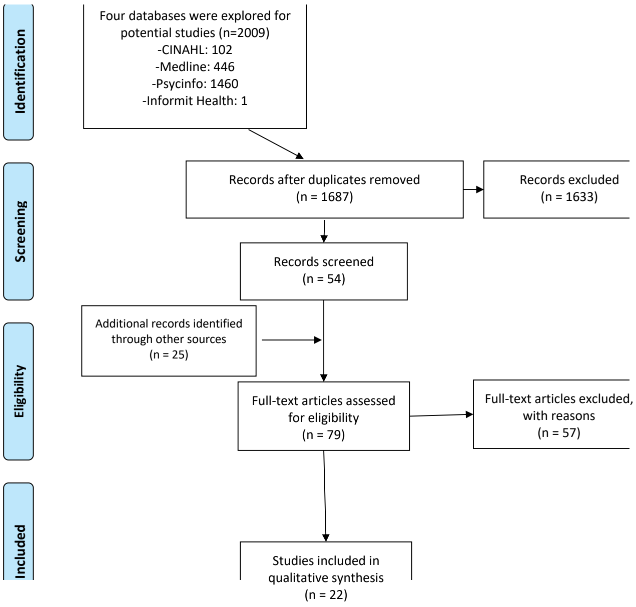

Figure 1: Prisma database search process

The quantitative measurements included: a) socio-demographic variables, such as personal information, socio-economic status, disease status and determination of rurality/rural classification; and b) health and wellbeing comparison between cancer patients in rural and urban areas, including a comparison of subjective wellbeing and functional performance. The health and wellbeing outcomes were divided into interconnected factors, such as physical, psychological, social and behavioural health, c) measuring disparity levels and impacts of proximity to treatment facilities on the treatment choices. This included factors such as travel distance, travel patterns, access to services and the related consequences such as financial burden.

The qualitative aspects of care needs, focused on overall experience of cancer survivorship in rural areas, the issues related to the service provision, receiving information by patients/caregivers, their communication with providers and experience of health care providers in service provision to rural cancer patients. The qualitative aspect of the research provided an in-depth insight to the barriers of care provision.

Both quantitative and qualitative measurements indicated that the concept of rurality was a risk factor for low mental health, low quality of life, low physical wellbeing, poor self-rated health, higher level of distress, smoking and lower level of physical activities[3,4,8,9,11,14,22,23]. A summary of the key variables/measurements for both quantitative and qualitative studies is provided in Tables 1 and 2.

Barriers and facilitators of care provision

Barriers and facilitators of the care provision were categorised into influencing factors at individual and system levels. Individual-level influencing factors concentrated on the socio-economic and/or psycho-social factors, while system-level factors focused on the community and organisational level influencing issues.

Influencing factors at individual level

Influencing factors at the individual level included socio-economic status, and psycho-social factors impacted the usage of health, social and community services.

Table 1: Quantitative measurements for health and disparity level in rural cancer patients

Variables		Measurements
Socio-demographic variables	Personal information	Age, gender, marital status/relationship status, children, race/ethnicity place of residence race/ethnicity, sex
	Socio-economic status	Income/annual household income categories, home ownership, employment status, educational level
	Disease status	Physical health measure Cancer-specific: type, location, time since diagnosis, stage, treatment schedule Co-morbidities (i.e., diabetes, heart disease, stroke, asthma), amount of treatment completed
	Determination of rurality/rural classification	Access to medical care Travel related to their cancer, including distances travelled to visit their general practitioner and their treating specialists
	Other	The experience of death of close social member
Health and wellbeing outcomes	Physical health	Self-rated health (single question) Medical Outcomes Study 36-Item Short-Form Health Survey Physical co-morbidity Medical outcomes study 12-item short form health survey Physical health measure/check-up
	Psychological and mental health	HLC (health locus of control) Life satisfaction Depression scale Mental Health Resource Questionnaire (MHRQ) Hospital Anxiety and Depression Scale Distress Thermometer Perceived Stress Scale QoL using the Functional Assessment of Cancer Therapy (FACT-G) questionnaire Quality of life — Cancer survivors scale; attitudes towards mental health resources Mental health outcomes Psychological functioning Coping Stanford Emotional Self-Efficacy Scale — Cancer Psychiatric Epidemiology Research Interview Life Events Scale CSMH resources (cancer-specific mental health resources) and Mood Disturbance; Evaluation of the Questionnaire on Distress in Cancer Patients — Short form (QSC-R10) The Patient Health Questionnaire (PHQ-4 measurement of depression and anxiety)
	Social health	Doctor–patient relationship Social support seeking CUCLA Social Support
	Behavioural health	Physical activity (single question)
Measuring disparity levels	Geographic location	Geographic location of patients residences compared to providers Matching the postcode to urban/rural residence
	Travel time	Calculating "the travel time by computing the road distance between two population centroids: the patients and the providers' zone improvement plan codes" Longitudinal cohort information in order to measure travel time to cancer treatment, living away from home for treatment, travel-related treatment decisions
	Disparity comparison	National health population characteristics Rural–urban residence; and their health status; to measure the disparity Locational and financial barriers to accessing care; financial and social impacts

Table 2: Qualitative variables exploring overall experience of cancer survivorship in rural area

Topic	Content
Information	- Physical aspect of the illness - Psychological aspect of the illness, including the first reaction to the illness, and how participants cope (emotionally and spiritually) - Social aspects of the illness (e.g., social burden, issues related to the social support perceived and received)
Services	- The services received by the individuals and their family members/carers - Disparities perceived about care provision by the individuals and their family members/carers - Patients and families feedback about the social, financial and informational /services/support - Barriers to seeking diagnosis - Perceived causes of and cures for cancer - Experiences with physicians and the out-of-hours services
Experience	- The experience of health providers (e.g., general practitioners) and their role in cancer management

The key socio-economic variables included education/health literacy/health-consciousness. A higher level of education and health literacy were among factors improving individual health beliefs, self-efficacy, understanding and attitude towards the service usage and help seeking[8,24,25]. This was particularly evident in isolated rural areas where limited resources often meant less anonymity of care[1]. Rurality was also related to a low level of information, lack of awareness or knowledge about the illness, available services, positive coping strategies[8,24,25], and lack of informational support[26,27]. One of the possible reasons for this could be the result of a lack of constructive communication between service providers and patients/family members[26,28]. In addition, living rurally results in lower access to the internet/health information and limited access to other social and community services, such as supportive survivors' cancer groups[8,22]. In an American study investigating the survival care plans, a lower percentage of rural people (62%) received advice regarding cancer follow-up care in comparison to urban survivors (78%)[23].

The key psycho-social factors included self-efficacy and confidence, which could be affected by fear, sadness, courage and faith in the health care system, as well as the informal social support received. These factors consequently impacted patients' engagement and treatment[28]. In addition, it was reported that patients with low emotional self-efficacy have a higher level of mood disturbances[25], which possibly impact their help seeking for support services. Some of the participants felt isolated and depressed as a result of being diagnosed with cancer and this continued during the process of treatment[28]. Cancer patients' perception about the informal support they receive (for example, strong family relationships/support) influenced their service usage[7]. However, too much reliance on informal social support such as family resulted in a sense of coping, decreasing the use of more formal services[24]. On the other hand, some of the cancer patients had concerns about family/children and being a burden to them[28] subsequently decreasing their problem sharing and help-seeking strategies with family[24].

Influencing factors at system level

The most common cancer burden at the system level in the rural area was related to the distance/travel burden, which can result in social and financial burdens[5,29-31]. Cancer survivors living in remote and rural areas had 17 times more financial and travelling burden[31]. In addition, travel burden resulted in the over-reliance on general practitioners due to limited access to specialist care[5]. Time and travel burden are of particular concern for those patients who may require more consultations or specific types of care due to undertaking specific procedures, or for older cancer patients[30,31].

Having a cancer diagnosis while living in rural areas can restrict the social inclusion of individuals in other informal and formal activities (for example, employment and recreation activities)[1,9,14]. Social concerns and their link to the lack of availability/accessibility of services resulted in a higher level of cancer burden. The review highlighted that limited services including community and social care support were available for people with cancer in the rural areas[1,26,28].

Fewer health professionals desire to work in rural areas (due to travelling, distance or isolation), particularly in some specific areas such as mental health, influencing the availability of rural services[9,32]. Corboy *et al.* suggested that appropriate health services and facilities must be available in the specific community to enable service use[24]. It was also reported that diminished quality of life, mental health and wellbeing of rural patients[1,22] are related to organisational factors (for example, limited mental and social services), and different psycho-social factors. The difference in societal acceptance of mental health in the rural community can be one of the main reasons impacting the creation of social and mental community support groups[1]. However, according to Corboy *et al.*[24], some of the cancer patients (particularly males) as well as health care providers suggested that lack of service availability is not the main reason of lack of service usage, but rather not being proactive to look for the right service they may require (which needs to be dealt with on an individual level).

Table 3: Characteristics and key findings of the included papers

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Andrykowski, Steffens, Bush, Tucker 2014 USA	To identify disparities in mental health outcomes in lung cancer survivors associated with ruralness of residence.	Quantitative survey Telephone interview	193 adults Lung cancer RR 26%	Demographic and clinical information, co-morbidity Medical Outcomes Study 36-Item Short-Form Health Survey Hospital Anxiety Depression Scale Distress Thermometer Perceived Stress Scale	- Poorer mental health outcomes in rural areas - Need to understand differences between different cancers	75% RR 26%	Lack of generalisation of the sample Need for longitudinal design
Andrykowski & Burris 2010 USA	To examine the use of mental health resources in rural and non-rural survivors.	Mixed-method survey Telephone interview	113 adults Rural: 51 Non-rural: 62 Breast, colorectal, haematological cancer RR 34%	Demographic and clinical information Mental Health Resource Questionnaire (MHRQ) assessing formal and informal mental health resources used	- No big difference between urban vs. rural - Poor access to mental services - Low level of social norm in access to mental health services in rural areas (stigma)	75% RR34%	Small sample size; measures did not cover all the mental health resources Need for extended research
Baldwin, Cal, Larson, Doble, Wright, Goodman, Matthews, Hart 2008 USA	To examine the travel patterns and distances of rural and urban colorectal cancer (CRC) patients to 3 types of specialty cancer care services — surgery, medical oncology consultation, and radiation oncology consultation.	Descriptive quantitative Cross-sectional retrospective	27,143 Patient records Colorectal cancer	Medicare survey claims analysed for: Geographic location of patients, their cancer care providers, the closest cancer care providers to their residences, distance in miles between patients and their actual or closest providers.	- Long distanced travelled for treatment - Need to understand cost benefit of services	100%	NA
Beck, Towsley, Caserta, Lindau, Dudley 2009 USA	To examine the symptom experience, quality of life, and functional performance of urban and rural elderly cancer survivors at 1 and 3 months after the completion of initial treatment.	Mixed-methods survey Semi-structured interviews	62 adults All cancers No RR identified @12% from reported numbers	Brief pain inventory-short form General fatigue scale Pittsburgh quality index Geriatric depression scale-short form Health-related QoL, functional performance inventory Qualitative interviews: story of the symptom experience	- High medical symptom burden for both rural and urban cancer patients - No significant difference in the illness symptoms in rural and urban areas - Low physical health status in rural cancer patients which shows higher level of treatment burden on this population in comparison with urban areas - Rural cancer patients require more education, knowledge and literacy regarding their illness, coping strategies and managing the symptoms of their illness	75% No RR	Small sample size for survey
Beraldi & Kukk 2014 Germany	To establish whether mental health outcomes, attitudes towards cancer-specific mental health resources, and the availability of such resources differ between rural and urban cancer patients.	Quantitative survey	534 adults Colorectal cancer RR 89% 3 sets of follow up	Demographic and clinical information Distress Thermometer Questionnaire on stress in cancer patients QSC-R10 Patient health questionnaire PHQ-4 Determination of rurality Attitudes towards mental health resources Definition and investigation of CSMH resources	- Overall, the knowledge and usage of the CSMH resources was low in both urban and rural areas; however, rural patients have a better doctor–patient relationship - Positive relationships between patients and health providers are even more important than the instrumental support facilities	100%	No documentation on refusal to participate
Bettencourt, Talley, Molix, Schlegel, Westgate 2007 USA	To examine the moderating influence of rural residence on the associations between health locus of control beliefs and psychological wellbeing in breast cancer patients.	Quantitative	224 women Breast cancer RR 60% incentive of $25	The Multidimensional Health Locus of Control Epidemiologic Studies Depression Scale Satisfaction with Life Scale	- Rurality impacts the health locus of control perceptions predicting psychological adaptation/adjustment. - Emphasise the positive role of the health care providers - Strong social networks, understanding culture and believes of rural people helps tailor strategies of treatment	100%	Modest recruitment rate Limited generalisation of the sample mainly Caucasian and Missouri

Table 3: Characteristics and key findings of the included papers (continued)

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Burris & Andrykowsk 2010 USA	To identify disparities in mental health outcomes between rural and non-rural cancer survivors.	Quantitative survey Telephone interview	116 adults 54 rural, 62 non-rural Breast hematologic colorectal cancer RR 34%	Demographic and clinical information Medical outcomes study 12-item short form health survey Hospital anxiety and depression scale Distress Thermometer Satisfaction with life scale Benefit finding questionnaire Quality of life–Cancer survivors scale	- Poor mental health in rural areas such as depression, anxiety and distress - Mental health disparities in rural areas Interventions required for increasing the usage of mental health services - Lack of desire to work in the rural areas by professionals (due to travelling, distance)	75% RR34%	Small sample size Lack of a healthy control group
Chan, Hart, Goodman 2006 USA	To compare the travel times, distances, and physician specialty mix of all Medicare patients living in Alaska, Idaho, North Carolina, South Carolina, and Washington.	Quantitative retrospective design	2220841 patient records Medicare billing data.	Travel time for patients in relation to medical care and speciality care.	- Low access to health care providers especially in terms of access to specialists - Over reliance on the generalists/GPs for health issues - Few health care visits and long distance travelling	100%	Including 5 states, which limits the generalisation of the study; old data which may not indicates the current trends
Corboy, McDonald, McLaren 2011 Australia	The current study investigated perceived barriers to support service use among such men, within the framework of the Behavioral Model of Health Service Use.	Mixed-method survey Semi-structured interviews	82 men Prostate, other cancer No RR	Demographic information Awareness and use of services offering emotional support, psychosocial support Reasons for participation in formal support services	- Low level of participation in formal support - Service availability was not a factor of participation - Influencing factors: family support and health beliefs	100%	Small sample size, with focus on prostate cancer
DiSipio, Hayes, Newman, Aitken, Janda 2010 Australia	To examine the quality of life, measured by the Functional Assessment of Cancer Therapy (FACT) questionnaire.	Quantitative, longitudinal survey	1140 adults Urban n = 277 Non-urban n = 323 Breast cancer	QOL Functional Assessment of Cancer Therapy (FACT-G) questionnaire 12 months post-diagnosis	- Quality of life related to breast cancer was low in rural areas - Lower physical wellbeing in the rural areas	100%	NA
Garrard, Fennell, Wilson 2017 Australia	An exploration of adaptive functioning in rural families following a parental cancer diagnosis.	Qualitative family semi-structured interviews	10 families 34 participants General cancer RR 69%	Resiliency model of family adaptation	- Strong family relationships valued - Need for communication within family - Families who identify as low-functioning are likely to benefit from interventions that promote adaptive communication and problem-solving skills	100%	Small sample size, lack of generalisability
Hanks, Veitch, Harris 2008 Australia	To identify and compare the roles of urban, rural and remote general practitioners (GPs) in colorectal cancer (CRC) management.	Qualitative semi-structured interviews	15 general practitioners in rural areas Colorectal cancer RR 71%	NA	- GPs provide holistic care including clinical, coordination and psychosocial care of the rural patients in comparison with the urban patients. - More research is required to explore the factors helping GPs to work more effective/productive in the rural areas	100%	Small sample, limited in geographical spread
Livaudais, Thompson, Godina, Islas, Ibarra, Coronado 2010 USA	Cancer survivorship experiences were explored among Hispanic men and women with cancer and family members of cancer survivors.	Qualitative focus groups	31 women, 10 men General cancer No RR	Barriers to seeking diagnosis, reactions to and challenges faced after diagnosis. Experiences with physicians, available sources of cancer-related information.	- Disbelief/fear/sadness VS. strength/courage/faith, and hope were the main answers to the diagnosis - Psychological issues such as depression, isolation, worried about family - Negative experience with the professionals, need for appropriate information, positive communication - Connecting the survivors to different peers and support groups beneficial	100%	NA

Table 3: Characteristics and key findings of the included papers (continued)

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Palesh, Shaffer, Larson, Edsall, Chen, Koopman, Turner-Cobb, Kreshka, Graddy, Parsons 2006 USA	To evaluate the relationships of emotional self-efficacy, stressful life events, and social support with mood disturbance among women diagnosed with breast cancer who live in rural communities.	Quantitative Structured interview using survey	82 women Breast cancer RR 82%	Demographic and Medical Characteristics Stanford Emotional Self-Efficacy Scale–Cancer Psychiatric Epidemiology Research Interview Life Events Scale UCLA Social Support Inventory Mood Disturbance	- Low emotional self-efficacy in rural women with breast cancer which can results in more mood disturbance - More education programs/interventions required for enhancing the self-confidence and positive coping strategies to stressful life-events - More comparative studies for the differences between level of social support in rural and urban cancer patients	100%	Cross-sectional design; very limited ethnic variability (predominantly Caucasian).
Paul, Hall, Carey, Cameron, Clinton-McHarg 2013 Australia	To explore patient experiences of barriers to accessing care and associated financial and social impacts of the disease. Metropolitan versus non-metropolitan experiences were compared.	Quantitative Self-report survey.	268 adults Haematological cancers RR 37%	Socio-demographic and disease characteristics Locational and financial barriers to accessing care Financial and social impacts Depression anxiety stress scale	- Cancer survivors living in remote and rural areas had 17 times more financial and traveling burden - More flexibility is required for cancer patients who are still in workforce - Addressing service disparities due to the distance is paramount in order to also decrease the other social and financial burdens	75% RR 37%	Low response rate; cross-sectional design limiting the causative effect between barriers and impacts; under-representation of the barriers/impacts experienced by the full-time workers at the time of their diagnosis
Reid-Arndt and Cox 2010 USA	To examine the extent to which rural residence and social support seeking are associated with quality of life among breast cancer patients following chemotherapy.	Quantitative Survey	46 women Breast cancer No RR	Rurality Social Support Seeking Hesitation scale Psychological Functioning Beck depression inventory Functional Assessment Cancer Therapy –Breast	- Rurality is linked with lower subjective and functional wellbeing, lower quality of life	75% No RR	Small sample size
Selman, Higginson, Agupio, Dinat, Downing, Gwyther, Mashao, Mmoledi, Moll, Mpanga, Pannajatovic, Harding 2009 South Africa & Uganda	To explore the information needs of patients with progressive, life limiting disease and their family caregivers.	Qualitative Semi-structured interview	90 adults 38 family caregivers General cancer HIV No RR	Exploration of issues related to the illness Family roles and support Informational support and needs Believe in any religion/god;	- Lack of informational support from health providers results in using alternative sources of the information - Lack of constructive communication between patients and health providers - Recommendations for more effective and informative communications between patients/carers and health care providers Tailored support recognising family and cultural beliefs	100%	Variations in interviews and disease states limits generalisability
Schlegel, Talley, Molix, Bettencourt 2009 USA	The current study quantitatively examined the coping strategies employed by both rural and urban breast cancer patients while they were undergoing radiation therapy.	Quantitative descriptive Survey	232 women Breast cancer RR 93% survey completed in clinic	Socio-demographic and disease characteristics Rurality COPE scale Depression CES-D	- Active coping and behavioural engagement strategies are important in decreasing the depressive symptoms in rural patients	100%	Convenience sampling may reduce generalisability
Schootman, et al. 2013 USA	Comparison of risk behaviours, psychosocial factors, health outcomes, quality of life, and follow-up care of rural and urban cancer survivors in Missouri.	Descriptive quantitative Telephone interview	9530 adults with cancer RR 59%	Socio-demographic and disease characteristics Patient health questionnaire Self-rated health	- Poor self-rated health, distress, and lower level of physical activities due to the limitations were reported more in rural populations. - A lower percentage of rural people (62%) receive advice regarding cancer follow-up care in comparison to urban survivors (78%)	100%	

Table 3: Characteristics and key findings of the included papers (continued)

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Weaver, Geiger, Lu, Case 2013 USA	To estimate the number of adult cancer survivors who reside in rural areas of the United States and to describe their self-reported health status relative to urban survivors.	Descriptive quantitative National Health Interview and Survey	30,000 to 40,000 surveys of adults with self-reported cancer RR 70%	Population Characteristics Rural-Urban Residence Medical outcomes SF-36 single question Kessler K-6	- Higher percent of rural survivors were non-Hispanic white, had lower level of socio-economic status - Worse health in all domains, poor health, psychological distress - Higher level of unemployment due to their health issues	100%	Use of self-reported rather than registry-confirmed cancer history.
Worth, Boyd, Kendall, Heaney, Macleod, Cormie, Hockley, Murray 2006 Scotland	To explore the experiences and perceptions of out-of hours care of patients with advanced cancer, and with their informal and professional carers.	Qualitative In-depth interviews, Focus groups Telephone interviews	36 patients and carers with advanced cancer No RR	The call to the out-of-hours service (background to the call, decision to make the call, what happened during the call, what happened after the call?); How the out-of-hours services can improve? Issues regarding the out-of-hour services.	- Not enough services for home care - Hesitation for using call-out-of-hour services - Positive experience of informational support from the staff assist recovery journey	100%	Difficulties for recruiting patients at the end of life, resulting in selection bias
Zucca, Boyes, Newling, Hall, Girgis 2011 Australia	To describe travel burden and travel-related financial burden experienced by cancer patients over the first year after diagnosis.	Descriptive quantitative Self-report survey	1410 participants City: n = 890 Rural: n = 520 General cancer RR 44%	Socio-demographic and disease characteristics Travel time to cancer treatment, European organisation research and treatment cancer quality of life questionnaire EORTC QLQ-C30 Single item from Supportive care needs survey	- Travel burden for rural cancer patients which is associated with high financial burden. - More attention is requiring for travel and accommodation schemes to address the travel and financial burden and decrease the level of disparities	75% RR 44%	

Discussion

Disparities in health care provision as well as social and community support services have a major impact on the health and wellbeing of rural cancer patients[9,29,31]. This review highlighted the influencing factors to care needs of rural cancer patients. Exploration of individual aspects of stress, coping and adaption were linked to influencing factors at system level such as rurality, access, availability of services and existing support system[9,29,31].

The analysis of the measurements used across the included articles highlighted the disparity of scales used and the difficulty in combining data to obtain higher level understanding of the experience and care needs of rural people with cancer. Two main areas were explored including health and wellbeing outcomes and inequality of care provision. Understanding the relationship between distance and travel time to the health outcomes provided an understanding of how the rurality increased the risk of lower health outcomes. Health and wellbeing had four areas of focus, which were explored to highlight the relationship between physical, mental, social and behaviours health in relation to remoteness.

Low self-efficacy was considered as one of the key barriers at the individual level in rural patients. Patients living with cancer may have feelings of hopelessness, lower level of quality of life and higher level of stigmatisation[9]. This can be due to experiencing a lower level of psycho-social support such as community and informal social support[9] as well as active coping and behavioural engagement strategies[15]. Self-efficacy can be improved by tailored support and a focus on communication between health care providers and patients[20]. The positive role of health care providers[11] has been showed to be even more important than the financial and instrumental support facilities[21]. Improving family support services and community-based models of support is paramount for support for rural patients on return to their home[7,24].

During treatment for cancer the patient is often closely supported by their carers and family members, thus there is significant disruption to the normal carer support processes[33,34]. This may place extra stress and burden on carers and they may suffer negative-related health care problems due to challenges related to the cancer and treatment of their family member[35]. A model of care which is patient- and carer-centred promotes the capacity of the patient to link with resources which are tailored to both them and their carer[36]. The current review indicated that the care needs and support services carers may require has been under-examined. However, the inclusion of the carers as part of the unit of care and empowering the patient and carer to be active is decision making enhances the strengths, wellbeing, capability and knowledge of the carers.

Distance and travel burden was one of the influencing factors highlighted at the system level, leading to other social and financial burdens[22,30,31]. For example, there are few rural areas providing advanced levels of medical and surgical services[22,30], resulting in travelling long distances for treatment and being away from the family. According to DiSipio *et al.*[22], women with breast cancer have to travel long distances (100 kilometres) and may be away from their home for 20–43 days for chemotherapy and radiotherapy, respectively, resulting in extra burden on the patients and their carers (for example, time burden, financial burden, and work burden) and subsequently may influence their quality of life.

In order to address travel and distance barriers, it is paramount to provide support for travel and accommodation for individuals/carers, which also help with financial burden and decrease the level of disparities[29]. However, it may also be important to consider the cost-efficiency of these services in rural areas. Another solution is to encourage health professionals to work in rural areas to reduce the burden of travel[37,38], particularly in mental health areas[9,32].

Community-based programs and family support services are needed in the local communities to build the capacity of individuals/carers and enhance the supporting social activities[9,26]. Connecting cancer survivors to peers and support groups may help rural cancer patients and their carers to enhance their social abilities, information sharing, emotional support/advocacy support, and increase their access to more financial and/or instrumental resources[28]. Having access to diverse sources of social support systems provide a type of insurance, a sense of belonging to a caring community, where help could be provided, if needed[39]. However, the interventions need to be aligned, considering the specific characteristics of the rural cancer patients[26]. Patient-mediated education and tailored support ensure that characteristics of the patient such as age, gender, health literacy, ethnicity, rurality and carer relationship are considered[40].

Recommendations for further research

Further research is required to explore the modifiable factors influencing disparities in rural areas[1]. Both individual and system level variables should be considered including: spatial, social, economic, and cultural factors in rural areas which influence the treatment and survival of rural cancer patients[11]. Longitudinal studies exploring the lived experience of survivors would provide a depth of understanding into the experience for rural patient and their families[11].

The important role of caregivers and/or family members in the recovery journey was highlighted by the research[26,27]; however, there is a lack of depth with this focus[41]. Further studies which specifically focus on the care needs assessment of the carers, family members and close social ties of rural cancer patients would provide a deeper understanding of the patient and family trajectory. It is also recommended to engage consumers and their carers in cancer programs to formulate ways to address diverse factors at individual, organisational, and community levels that impact services access and use[42].

Conclusion

The provision of holistic health care for rural people has challenges related to distance and cost. All the articles in this literature review demonstrated that the level of disparity is due to both the need to travel to receive care and the lack of quality care closer to home. However, there is limited focus on the carers and family members' burden during illness and treatment, leaving them at risk of physical and psychosocial distress. Future studies could consider modifiable factors which include the disparities in rural areas. Patient-mediated education and tailored support should be considered in order to provide an efficient and practical support to the family as a unit of care to ensure a holistic approach to recovery.

Limitation

Although this study aimed to explore the key influencing factors to care provision to both patients and carers as a unit of care, only two qualitative studies focused on the cancer patient and their carers as a unit of care.

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Conflict of interest

There are no conflicts of interest for any of the authors. The authors alone are responsible for the research process, analysis and writing of the paper.

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Access to breast cancer screening — perception, and perceived barriers among older Bhutanese refugee women resettled in Australia: a qualitative study

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Abstract

Background The use of breast cancer screening mammogram is proven to be beneficial for the early detection and prevention of breast cancer. Despite the free availability of this service in Australia, it has not been fully used by many migrants and refugee women.

Objective To explore the perception and perceived barriers of Bhutanese refugee women to the access and use of breast-screening service.

Methods We used qualitative methods with an in-depth interview and Interpretative Phenomenological Analysis (IPA).

Results Our findings suggest that there is a low level of screening services use among Bhutanese refugee women. From the interpretative phenomenological analysis of the interview data, four main themes were apparent as barriers to accessing breast cancer screening: lack of knowledge about the importance of the screening; lack of motivational factors; problem-triggered health seeking behaviour due to strong cultural factors; and communication difficulties due to poor literacy and limited English language proficiency — all have contributed to low-level use of breast-screening mammograms.

Conclusion Older Bhutanese refugee women resettled in Australia did not seek preventive screening without symptoms or their doctor's advice. Women in this study followed their doctor's lead. Recommendations for screening and follow-up from their doctor were followed, and lack of advice from them was interpreted by the women that no action was required.

Introduction

Breast-screening is considered one of the most effective methods of improving survival of breast cancer. A national breast-screening program has existed in Australia for more than two decades[1]. In Australia, biennial breast-screening is recommended, free of charge, for women aged 40 or more, while women aged 50–74 years are sent invitations from BreastScreen Australia[2]. The aim of the screening program is to improve health outcomes in an asymptomatic population by detecting conditions associated with elevated cancer risk and early-stage cancers, where treatment will be effective[1]. Over the 20 years since the full implementation of the breast-screening program in Australia, it has been estimated that this program reduced breast cancer mortality by 21 to 28 per cent[2]. However, the service access and utilisation rate in Australia among migrant and refugee women is significantly lower compared to rates in the host population[3, 4].

Breast cancer is the most common cancer diagnosed in women and accounts for approximately 28% of all cancers in Australian women[5]. Though early detection and appropriate treatment can effectively improve breast cancer survival, marked disparities have been documented in the uptake of breast-screening among ethnic minority populations[6].

Australia has resettled more than 6000 Bhutanese refugees under the United Nations' humanitarian program as part of a coordinated international strategy[7]. We could find no studies that have explored breast cancer and the Bhutanese refugee population in Australia, but studies in the United States (US) have highlighted the low rate of participation in cervical and/or breast-screening programs among this group[8-10].

Several reasons have been suggested as contributing to low screening rates among refugee women, including poor comprehension of the concept of screening when such services are not available in the home country or country of asylum[6,11]. The aim of this paper was to explore Bhutanese women's perceptions and perceived barriers to accessing breast-screening programs in Australia.

Theoretical framework

This study was underpinned by an intersectionality theoretical framework where intersectionality as a theoretical framework creates a space for the exploration of how multiple social identities of women intersect to influence their own health behaviour[12]. Intersectionality allows exploration of multiple social identities among women through a multi-axial approach by taking account of their different roles[12]. The application of intersectionality in this study explored the interconnected factors affecting Bhutanese refugee women that can influence their health-seeking behaviour after resettlement. The types of factors that intersect include their race, their education level, their caste, traditional beliefs and practices, and socio-economic and refugee status. The interplay of these intersections is significant when exploring their health-seeking behaviours.

Methods

Data collection

Face-to-face, in-depth interviews were conducted in the Nepali language by the primary author (JP) between April 2016 and December 2016 in a separate room of the homes of study participants, with only the interviewer and interviewee present. The interviewer, who is a Nepalese Australian, worked as a refugee health nurse and previously worked in refugee camps in Nepal.

An interview guide, which had been developed, based on the literature, had minor modifications after the first three interviews to incorporate additional information recorded in the field notes. The interviews covered a broad range of questions relating to experiences of accessing cervical and breast-screening services. Photo elicitation was used to facilitate data gathering when women were unfamiliar with screening, with photographs of screening activities used to prompt understanding[13]. Data collection continued until data saturation was reached. There were no repeat interviews. Interviews took 30–60 minutes and were recorded, transcribed and translated into English. A sample of the interviews (10%) were independently translated by a second Nepalese-Australian PhD student enrolled at another institution. No discrepancies between translations were identified.

This paper is confined to a sub-sample of a larger study of 30 Bhutanese refugee women and to questions about breast-screening.

Study participants

Participants were purposively selected through information provided by Bhutanese community leaders. No one approached refused to take part. This sub-sample included 14 women aged 50–70 years. All had lived in Melbourne for at least four years (range 4–7 years), were born in Bhutan and lived in refugee camps in Nepal for at least 18 years (range 18–23 years). Most had never gone to school and were illiterate in their own language. All participants were married and had at least two children. Participants provided their own pseudonym, which confirmed their understanding that others would read their responses. Two women chose the same pseudonym, so superscript numbers were used to distinguish these.

Analysis

Transcripts were read and reread. Interpretative Phenomenological Analysis (IPA) was undertaken with the assistance of NVivo 11[14] for coding and data management. The six-step IPA process includes: looking for themes; looking for connections; producing a table of themes; continuing analysis with next case; creating a master list of themes; and writing up findings[15]. In the two-part interpretation process participants were asked to clarify or explain and the researcher interpreted how participants made meaning of their experience[16]. The primary researcher undertook the analysis as part of her PhD studies, with the co-authors coding subsets of the data for checking.

Ethics

Before each interview, participants were given a study information sheet in Nepalese, describing the study with information about confidentiality. This was explained in detail. Ethics approval was obtained from the University Human Ethics Committee (UHEC), at La Trobe University, Melbourne, Australia.

Results

Four main themes contributed reasons for low utilisation of routine breast cancer-screening mammograms among Bhutanese refugee women in Australia: lack of knowledge about the importance of screening; lack of encouragement; communication difficulties; and problem-triggered health-seeking behaviour. Those who had attended the services also talked about their experiences with breast-screening mammogram, which further clarified their perceived barriers to accessing services.

Lack of knowledge about importance of screening

Most participants knew little about breast-screening, and despite being in Australia for five years, only nine of the 14 women had had a mammogram. All nine had done so following a recommendation by their doctor, but there was still little understanding of the importance of screening, and only one of those who had a mammogram had followed up after two years. The five women who had never had a mammogram had also never heard about breast-screening.

> *"I do not know anything. You know, nobody tells us. I can't talk, read, it's like being dumb and blind here in this country. Not able to talk is the most hurtful thing in your life. Nothing is known about it." (Madhavi)*

Most women knew something about breast cancer, but some were unaware of the disease, including women who had been screened. A few women initially said that they didn't know about breast-screening but when shown photographs of mammogram screening responded "yes, I did this test".

> *"... It was hard to know what has been done. There was no interpreter." (Madhavi)*

Most women had no knowledge that screening tests are done to detect problems and saw no need for investigative tests if no symptoms were present.

> *"No feeling of pain, no discharge, felt no need to do it. Nobody told me about the importance of doing it. I didn't know this is for cancer prevention." (Rathi)*

Lack of encouragement

A common view among the women in the study was that as their doctor had not raised breast-screening it must not be important or relevant to them.

> *"When we go to the doctor, a doctor does not talk to us other than the problem. No one told us about this service and asked us to do it." (Sanu)*

The failure to hear about screening services from someone who the women saw as significant, like their doctor or informed family members or friends, meant that women did not see the importance of screening services, and so did not feel encouraged to use them.

> *"Firstly, I don't know about the service and no one is informing and encouraging us to do it." (Amma[2])*

> *"If women are informed by their doctor they would do it." (Leela)*

Most women who had accessed services had used them only once. Only one woman had followed up after two years and done so on the advice of her doctor. When others were asked why they had not followed up, the women said they had not been told about the importance of regular follow-up.

> *"I used it only one time. Nobody told us to do it again within two years and I didn't know." (Saraswata)*

Communication difficulties

Limited English and poor literacy were the major causes of communication problems. Thirteen of the 14 women interviewed had never attended school and did not know how to read or write, making face-to-face communication critical.

> *"If I was not told by my doctor I would not know to do it." (Devi)*

Women expressed frustrations with illiteracy strongly in the interviews. It is really frustrating for women when someone gives them a document to read when they do not know how to read.

> *"One thing is I feel very bad for is not knowing [how] to read and write. It seems like I have a black tape on my eyes. My parents are already dead, but I am now feeling how important it would be if they have given us some education at least to read and write. I feel like I want to read my own documents." (Saraswata)*

Lack of English was also a barrier to participation in screening because the women couldn't clarify any concerns. Several that had mammograms had agreed to the procedure knowing nothing about it.

> *"Here we don't speak the language. This is the main thing; that we are reluctant to ask any question if a doctor is not using an interpreter. We do whatever [the] doctor asks us to do. Then if the doctor doesn't tell about it, who would know." (Sanu)*

A common experience for these women was to have their children act as their interpreters, but the women did not like sharing sensitive health information when their children were present.

> *"Most of the women of my age go to the doctor with their children who can speak English. If I am going with my son, I do not like to talk about it [sensitive health issues] with him being an interpreter. This is the main problem as well. There is the barrier, no one talks about their personal problems with their kids there. No matter how old they are." (Sanu)*

Women disliked having a mammogram with no explanation, as Aama[1] described:

> *"Well, there was a woman doing this, it was very new, strange, painful and I did not know why I was doing it. Nobody told me why I am doing it. I didn't feel discomfort but when breast was put in the machine I had [a] little pain. There was no interpreter. My son was with me, but he stayed outside, I could not understand what she said, I didn't know why I am doing it. But I was there because I am female, I was told not to worry about it." (Amma[1])*

Problem-triggered health-seeking

Women in this group were motivated to seek health services only when symptoms were apparent. Problem-triggered health-seeking behaviour was a significant barrier to the use of preventative screening services.

> *"I have not used the service, because there is no pain, no problem." (Rathi)*

> *"I told the doctor that I have a lot of pain, burning sensation over my both breasts, I could not move my arms, the doctor asked me to go to do the x-ray." (Ganga)*

> *"As I was feeling a bit different in my breast, then I went to the GP and GP did some examination and sent me to do an x-ray." (Pabi)*

Aama[2] found lumps in her breast which led to a breast-screening mammogram.

> *"I started having check-ups after I had a problem. Many lumps appeared in my both breasts. But I was not scared of the problem, because I knew that it was due to the sour drink that I had in English language school." (Aama[2])*

Strong cultural issues were also attached to various health beliefs, for example, feelings of embarrassment about exposing certain body parts.

> *"... but initially I had not done this due to extreme shyness but later I did and they did find some abnormal mass in my breast, It means it's worth doing it." (Maya)*

Saraswata's experience of a mammogram was typical:

> *"I felt a bit uneasy, ashamed while exposing my breast, as I never showed this to anyone in the past, I closed my eyes and a woman assisted me to do that. I felt inside me this is only for good thing and that does not last for long. I closed my eyes until it finished. I am really shy." (Saraswata)*

Discussion

We explored the perceptions and perceived barriers towards breast-screening among older Bhutanese refugee women. The problem-triggered health-seeking due to their particular cultural values and beliefs was a significant barrier to accessing preventive care services in this study. Like other studies, communication difficulties and lack of knowledge about the importance of services were also prominent barriers to breast-screening[11,17,18]. Besides these factors, the study also identified poor health professional practices, specifically with the use of interpreters and in failure to communicate the importance of screening, as likely contributors to poor uptake of screening services.

The phenomena of problem-triggered health-seeking was a major theme throughout this study. Women sought health care only when symptoms were present. This behaviour was reinforced by the common belief that 'if it was an important health issue, our doctor should have told us'. Women did not know to ask about preventive screening, and their doctor and other health professionals failed to tell them. Preventative health care was an unknown concept to the women and their education about it was ignored by the health professionals caring for them. Other studies have observed that refugees are more likely to attend health care services when they are sick and symptoms are present[8] and that preventative health care is an unfamiliar concept[19,20]. Lack of education plays a part in this, but so too does extended periods in refugee camps where managing acute illnesses is the priority.

As in other studies[21,22], cultural beliefs and stigma were prominent barriers to accessing women's health services in this study. Such findings reinforce the need for healthcare professionals to recognise the importance of cultural norms for women from ethnic groups; for Bhutanese women, for example, shyness and embarrassment about exposing private body parts was clearly evident, and rated highly as barriers to attending screening mammograms, especially while no motivational factors emanate from an authoritative person, such as their doctor.

Our findings about poor knowledge about the importance of screening as a barrier to uptake of services, are consistent with other studies[23], and that knowledge of the link between breast cancer and screening can motivate women to undergo breast-screening[6]. Promoting cancer screening in this population of older refugee women, was obstructed by other factors, including illiteracy and the reliance on family members as interpreters. Women in this group regularly attended medical clinics, but had not been informed about, or offered any discussion of the free breast-screening program available to them. Health professionals need further encouragement to ensure the same level of services are provided to this vulnerable group. This could include training in the use of interpreters and how to provide health information to groups with special literacy needs[24]. Thirteen of the 14 women in this study were illiterate in their own language.

An important finding from this study was that women did not think that they needed breast-screening as their doctor had not advised them to do so. Women attended breast-screening services, and followed up, when their doctor referred them. However, referrals were made without explanation, which meant that women did not attend screening regularly. These findings are similar to another Australian study involving young refugees accessing mental health services[22], and raises questions about the level of cultural sensitivity among Australian health professionals.

Though most of the doctors' practices have various types of leaflets and other information sources available to serve the purpose of informing women, the information of breast-screen is either not given in appropriate ways, or not interpreted to the women in this study. Apparently, many of them did not know and didn't attend the breast screening program. Only one woman out of 14 in the study group was educated and literate, the rest have never gone to school and did not know how to read and write. This evidence indicates that the only way to provide information to these women would be a direct 'verbal communication' to them. One of the best strategies would be opportunistic education from a doctor, which would be very effective, as the doctor is perceived to be the most authoritative person to provide health information. One-to-one education from a doctor or other health professionals could be the most effective way to optimise screening mammograms uptake for Bhutanese refugee women. Other studies have found that poor health literacy and poor understanding of health care systems can be a prime obstacle for health-seeking generally among refugees after resettlement[18,25].

Limitations

The major limitation of this qualitative study was that it involved a specific Bhutanese refugee group of older women. Several of the perceptions and barriers identified to access to breast screen services were attached to the Bhutanese cultural context and beliefs. Although similar themes may be evident in other groups, findings of this study may not be generalisable to other refugee cohorts. The study took place in Australia, which has a universal health system and free interpreter services for refugees, conditions that do not necessarily apply in other high-income countries. Thirteen out of 14 women in this study were illiterate in their own language, had have language barriers hence, our study findings may not be representative of those who are literate and with no language issues.

Conclusion

Our study explored perceptions and perceived barriers to breast-screening among older Bhutanese refugee women after resettlement in Australia. The study provides a valuable insight to problem-triggered health-seeking behaviour that was collectively running in this group. Women in this study did not know to ask about screening services and their doctor and other health professionals failed to inform them. The issue of problem-triggered health seeking needs to be countered with effective education strategies that involve health professionals, particularly doctors. Women in this study followed their doctor's lead. Recommendations for screening and follow-up from their doctor were followed, and lack of advice from them was interpreted by the women that no action was required.

Conflict of interest

The authors have no conflicts of interest to declare.

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Cancer Nurses Society of Australia

Unmet supportive care needs of rural men with cancer: a qualitative study

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Abstract

Background A cross-sectional medical record audit and self-report questionnaire study of a rural supportive care cancer program found that when compared with women, men were more likely to be older; perceive health care information to be unhelpful; receive fewer referrals to services; were reluctant to join support groups and experienced a poorer quality of life.

Aim The aim was to explore unmet supportive care needs of rural men with cancer to inform improvements in service delivery.

Method Twenty-two men were invited to attend a focus group. The focus group was audio-recorded, transcribed verbatim and field notes were taken. Data were analysed thematically.

Results Ten men participated. Six key themes describe how these rural men perceive deficits in the cancer care support.

Conclusion There are unmet supportive care needs experienced by rural men with cancer. Gender-informed support is important when individualising care for men.

Background

Many people with cancer encounter severe physical, existential, and emotional problems[1]. In recognition of this, most Australian health care facilities have included supportive care screening (SCS) in their cancer care programs. SCS is a systematic, evidence-based approach intended to identify and prioritise care needs for cancer patients. Supportive care is defined as *"the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement"*[2].

Screening for care needs is recommended to be routine and periodic at various stages of the cancer experience[3]. A validated and widely used screening tool, developed by the National Comprehensive Cancer Network, is the Distress Thermometer (DT) and Problem Check List[4]. The level of distress experienced is identified on a 0–10 scale; a score ≥4 may indicate significant distress. The score identified on the DT is intended to guide clinical decision making. The Problem Check List enables identification of issues in the past week related to practical, family, emotional or physical problems and spiritual/religious concerns. The ideal outcome of screening is that individual risk factors are considered and appropriate actions and referrals to specialised services are matched to the patient-identified needs.

Poor quality of life (QoL) post-cancer treatment is common for men[5]. Previous studies have shown that men with cancer experience some very specific unmet needs[6]. A large systematic review focusing on the supportive care needs of men living with and beyond prostate cancer describes problems related to intimacy, lack of clear information, physical and psychological distress[7]. Significantly, while men view information needs as most important, the greatest unmet need in one study, again focusing on prostate cancer, is the type of information — specifically the recurrence of cancer and side effects of cancer and its treatment[8].

In an optimal patient-centred approach, greater patient satisfaction and improved outcomes is more likely when care is tailored to the whole context[9]. Depending on the environment, men or women may adjust their behaviour in certain ways. Recent research recognises the importance of understanding the interaction between gender and other variables, such as age and class when experiencing cancer[10]. Further, there are key cultural expectations of what it is to be a cancer patient[11]; negative thoughts and expressions are generally not acceptable and 'thinking positive' is viewed as a moral imperative.

Concomitant with culture is the role of gendered expectations of behaviour. There is evidence internationally that medical institutions 'gender' their practice in the care of men and women with cancer[10] in a way that can, at times, subconsciously stereotype men and women into traditional expressions of masculinity and femininity[10]. Problematic too is that the majority of research on counselling in cancer care has been with women and breast cancer. Past research reports that counselling is universally seen as beneficial to cancer patients, *especially* women[12].

Survival rates for cancer are lower for rural-dwelling Australians than urban dwellers[13] and thought to be linked to their higher rates of socio-economic disadvantage, more advanced cancer stage at diagnosis and limited access to specialist cancer treatment. People living in rural areas have less access to health services, with shortages in almost all health professions and health-related infrastructure[14]. Lower levels of education in rural areas also results in poorer knowledge and negative health behaviours, which predispose rural Australians to cancer[13]. Although survival rates for rural Australians have improved in the past 30 years, the incidence of cancer continues to increase[15].

This study was part of a larger project which aimed to evaluate the effectiveness of SCS in a rural ambulatory cancer care service in Northern Victoria[16]. Primarily males were found to have poorer QoL, with characteristics, such as needing to rest in a "bed or chair", "feel[ing] weak" and experiencing "shortness of breath" more than females[16]. Moreover, men found that the information provided by the cancer support team was "less helpful" than women did, despite having more visits to the health service[16]. Men were also more likely to be older than women and less likely to receive a referral through the SCS process[16]. Added to that, men were less likely than women to declare any positive benefits from the cancer experience, nor attend support groups or ask for information[16].

The aim of this study was to follow up on the findings from the previous study and describe the unmet needs of these rural men with cancer to ultimately inform improvements to the SCS program.

Recruitment

Twenty-two men in treatment or remission from cancer consented to participate in further research as part of the evaluation of SCS research conducted at a rural ambulatory cancer service in Victoria, Australia. This evaluation has been reported elsewhere[16] and provides the background to this study. Participants were contacted by telephone and invited to participate in a focus group at a time that suited the majority.

Method

The focus group was held in a local community library and facilitated by a faculty staff member who had no previous role in the research study or relationship with the focus group participants. The facilitator was a male academic with a nursing background and previous qualitative research experience. The principal researcher and a co-researcher (both nurses and rural health research academics) also attended the focus group interview and field notes were recorded by both researchers. The focus group followed a semi-structured question framework drawn from the findings of the first study, which aimed to stimulate discussion about individual men's experiences of cancer while living in a rural area. The duration of the focus group was 78 minutes and was audio-taped and transcribed verbatim.

Data analysis

The transcript was coded by two researchers to identify themes related to distress, against the contextual backdrop of rurality. Participants are not identified to preserve confidentiality and quotations are presented to illustrate themes. Field notes are provided to further illustrate and support the identification of the themes.

Results

Eleven men agreed to participate and 10 attended the focus group. Reasons for non-attendance were not sought. The major themes identified included the need for support groups specifically for men, financial distress as a result of their illness, relationship breakdown, cancer myths, knowledge gaps about cancer and treatment, and coping with physical limitations resulting from their illness or treatment.

Focus group demographic and descriptive profile

On average, the men in the focus group were 70 years of age (range 53–84). One man did not provide further demographic characteristics. Of the remaining nine, seven lived within 25 km of the health service where SCS took place, four had multiple diagnoses, three colorectal cancer, one melanoma and one lung cancer; all had been diagnosed more than 24 months earlier, five had received treatment at another hospital other than the health service in which the study was conducted, five had more than 21 visits to the local health service.

Support groups for men

There was a clear and repeatedly expressed desire for a support group specifically designed for men. Field notes record that many focus group participants mistakenly believed that the focus group itself was intended as a support group. Participants perceived that formal support groups were available for women, yet in their experience no formal or informal support existed for men.

> *"There's nothing else around really for blokes to sit down and have a yarn, is there?"* (Participant 2)

> *"Getting a group of blokes like this sitting around you can all have a yarn, let out some of your problems and it helps, I reckon."* (Participant 4)

> *"... you have these things for women where they go in to have nails done and their hair done and that. I said there's nothing for blokes, what about getting something like that going for us blokes?"* (Participant 5)

The men expressed feelings of seeking yet resisting support. While agreeing that support groups were something they wanted, they also were mindful not to appear too needy. Negative terminology such as "complain", "whinge" and "sook" were used throughout the dialogue. They appeared to be 'checking in' with each other that it was OK to want to meet and talk about their experiences. Field notes during this discussion recorded *"... the group have erupted, all talking over the top of each other, there is much ad lib humour, laughter and comical agreement, a form of 'pack camaraderie', almost as is if there is a fear of seeking help as a consequence of appearing weak".* (Interviewer 3)

Financial stress

Financial distress was raised by many of the participants. Several told stories of seeking help, but were frustrated by the process and their inability to change their circumstances. The men described strong emotions of powerlessness in the face of bureaucracy. Comments included:

> *"I had six months of chemo. Got no insurance, no nothing so I was six months unemployed ... we had to go around and see everyone that we owed money to, the banks and yeah, six months of chemo ... we went from two incomes to none. We had no money. The time we met there, well interest only on the house loan, still had three kids living at home out of five — by the time with food and a bit of fuel we had nothing to come back over here [health service for treatment]. That's the hardest part. I couldn't get unemployment benefits. I couldn't get nothing. Even though the doctors said you're entitled to this you'd go to Centrelink [Australia's national welfare agency], [they] don't want to know you."* (Participant 4)

> *"... my missus was only getting holiday pay or long service the first five months I was crook. She was at home looking after me, so she went to that mob and said well I should be able to get a carer's pension or something. At the end of it after six or eight months of fighting and yelling and screaming and scratching and biting and stuff I was getting $64 a week."* (Participant 2)

Field note records detected a sense of anger during this discussion, particularly expressed by the younger men in the group, who were suddenly unable to work and thus contribute to the household income during treatment. The group agreed that the Ambulatory Cancer Service had on occasion provided 'petrol' and 'bills' money, a mere insignificance it seemed amid the enormity of the financial stress felt.

Relationship breakdown

Some of the participants related stories of relationship breakdown, during or after their cancer treatment. It was unclear if they had sought counselling or emotional support during this period. Comments included:

> *"... my wife told me it was all over and done with, so I walked away from a 33-year relationship with her...*
> *"... when the ex-told me it was all over I just — it wasn't the end of the world because I'd been to the end of the world."*
> (Participant 4)

Field notes record a sense of 'impotence' related to the loss of agency and control as well as loneliness and despair experienced during phases of the cancer journey.

Cancer myths

Many of the participants demonstrated that they had a poor understanding of cancer, associated risk factors and causation. It was clear that education or information relating to cancer may have been useful to increase their understanding. Comments included:

> *"Where's it come from? ... well, it's in our bloods somewhere, DNA."* (Participant 2)

> *"One of my mates years ago, footy player, he got a flick in the gonads with a towel after training one night. Cancer not long after."* (Participant 5)

Knowledge gaps

As well as a poor understanding of cancer aetiology, many participants expressed that they had little knowledge of the treatment they had received, the reoccurrence of illness, or where to access information about their illness and treatment. Comments relating to this include:

> *"When I was told I had leukaemia I said yeah, yeah, fine what's leukaemia?"* (Participant 1)

> *"I didn't have much of a clue about it ..."* (Participant 2)

> *"I don't know if it's true or not, that cancer ..."* (Participant 3)
>
> *"I had a lung removed ... and I don't even know the name of the doctor that did it. Never ... I was never told ... well I didn't know who to ask."* (Participant 6)

Physical distress

Physical symptoms related to cancer or treatment was discussed in light of the effect this had on their day-to-day life and interests. Comments illustrating this were:

> *"You get up to do something and you might be alright for half an hour then you just run out of puff and go and sit down."* (Participant 2)
>
> *"Sometimes I've just got to go to bed for a couple of hours in the middle of the day."* (Participant 5)
>
> *"I've never slept during the day in my life. I can't go to sleep in a car when it's travelling [normally]. The last three months I can sit down in the chair at five o'clock in the afternoon and have a 10-minute nap"* (Participant 2)
>
> *"I had to give up golf because my right leg would collapse every time I tried to hit the ball. That was the end of the golf."* (Participant 5)

Recorded field notes indicate that during this discussion, men appeared in genuine shock at how tired they felt and their subsequent inability to participate in the activities that were routinely a part of their life before their cancer diagnosis. More than this, men appeared to be frustrated with a need to alter their activities of daily living to accommodate their physical changes:

> *"... I've got this app on my phone ... — now I know every toilet in every town because ... if I eat the wrong thing now 20 minutes later I've got to find a loo."* (Participant 4)

The focus group concluded, with many of the men asking when another gathering would be held, some again mistakenly believing that the focus group was, in fact, a support group meeting.

Discussion

This study aimed to explore the experiences of a group of men in a rural Australian region who had undergone SCS during their treatment for cancer. Six themes emerged in the research: the need for support groups for men; financial stress; relationship breakdown; cancer myths; knowledge gaps; and physical distress.

Many people diagnosed with cancer are receptive to informal supportive care[17]. The men in this focus group perceived emotional and social support via a specific men's group as desirable, but lacking in comparison to that available for women in the region. In common with our findings, a large international study identified that men felt less informed about psychological support; however, in contrast to our study, the men expressed fewer needs than females[18]. While informal caregivers, such as partners, close family members, or friends, have been shown to provide essential support to cancer patients along the illness trajectory[19], the men in this focus group seemed quite clear that they needed something outside of the family. Cancer patients report benefits in sharing experiences with others[20]. Rural people, men in particular, are portrayed as being more stoical and less likely to ask for help[20]. This may explain why in tandem with identifying limited access to informal support as a contributor to their isolation, the men were careful to ensure that they were not being perceived as weak. They expressed this in the use of colloquial terms such as "wimps" or "sooks:". It could be that while wanting to have similar supports as women's groups they were keen to ensure this was not in conflict with their "masculine identity"[21,22]. For this group of men there was an obvious tension of wanting to have what the women had but ensuring that they were "not being like women"[23].

It is well known that cancer places a financial and economic burden on individuals[24,25]. A study of patients with colorectal cancer highlighted the adverse impact of treatment and employment[26]. Moreover, McGrath *et al.*[26] demonstrated work limitations resulted in financial hardship for those recovering from cancer. Economic stress experienced by the men in this focus group was related to an inability to attend to their usual employment as a result of their symptoms from cancer or the treatment they received. The anger of finding oneself in extreme financial chaos was described by one man with the words "fighting and yelling and screaming", illustrating a loss of control over the circumstances that a diagnosis of cancer had put him in. The men in this group shared a common difficulty in reconstructing a former sense of themselves as powerful, strong men and breadwinners. The negative financial impact of cancer seems to be well known, yet the men in this focus group expressed extreme frustration at the barriers they faced in seeking timely and adequate monetary assistance. The need to travel for treatment for those living in rural areas compounds this financial hardship[20], and this was expressed by the men in this group. Addressing cancer-related financial burden has been identified as improving overall QoL[27]. Improved access to financial assistance may have ameliorated stress related to cancer diagnosis and treatment for these men and is an area that needs urgent attention from social services.

A lack of control or agency was evident in other aspects of life, aside from financial control for the men in this focus group, which may be related to their age. On average, these rural men were around 70 years. Moynihan's[10] early research identified a paucity of evidence of how older men with cancer respond to formal support, despite the knowledge that prostate cancer patients exhibit untreated distress. Moynihan[10] also proposed that assumptions about older men and their self-perceptions when experiencing illness in addition to the clear lack of services for men may be a contributing factor for distress. The rural location of this study means that, although 70 years of age, many of the men may still be self-employed in agriculture, adding another layer of complexity for distress that does not exist in urban studies.

The men in this focus group reflected on their changed intimate relationships and, in some cases, relationship breakdown. There is good evidence from a previous Australian study that cancer does impact on intimate relationships, with changed roles, communication, intimacy and sexuality[28]. The changed roles frequently results in sadness, anger and frustration, but can result in relationship enhancement for men, more so than women. The feelings expressed by men in this study support these earlier findings of relationship changes, although for one man in particular his relationship deteriorated irreconcilably rather than improved. Gilbert *et al.*[29] describe these changes as "biographical disruption" and are, in part, a result of the physical impact of cancer, which forces men to adjust their daily life to accommodate physical needs. The stoical characteristics of rural men mean they may not adjust as well as their urban counterparts to "biographical disruption", increasing their level of distress.

It was evident in this focus group that there was a very poor knowledge of cancer and subsequent treatment. An Australian study focusing on prostate cancer showed similar issues with men's knowledge, concluding that informational support is a priority for men[6]. Interestingly, a small recent study reported that written information is less useful to men compared to clinical consultations, which may have implications for ways in which clinicians communicate information to men[16]. This may account for the high number of visits to the health service by some of the men. Informational support is shown to be a short-term need[30], but is associated with quality care[31]. Informational needs include the stage of disease, treatment options and side effects of treatment, as well as the trajectory of recovery[31]. Health professionals are the most frequent source of information in cancer care [31]. Irrespective of gender, patients who are less satisfied with the information they receive report more anxiety, depression, and lower QoL[18]. The comments in the focus group, such as, "I don't even know the name of the doctor that did it" suggest a real power imbalance and lack of information sharing. While research confirms that older age groups are less likely to engage in, or demand, shared decision making about treatment options[32] this can result in future decisional regret. In addition, rural people are more accepting of a paternalistic culture of care and express less preference to be involved in treatment decisions[33]. For this cohort of men, both older age and rurality, mean there may have been greater acceptance of the lack of information sharing about their illness and treatment.

Cancer care, like all health care, requires a person-centred approach. An Australian study showed that oncology nurses who provide supportive care should be aware of differing attitudes among their patients[34]. Our study supports these findings and strongly suggests that when considering the 'apparent' attitudes of men to suggested supportive care services and resources, clinicians ought to reflect that attitudes are highly influenced by the broad cultural context which includes, age geographic location and gender. Rural men, especially older men, are unlikely to request information about their illness or demand greater involvement in decision making about treatment. A model of shared decision making in SCS, including ascertaining the patient's preferred level of involvement, their understanding of illness and treatment pros and cons and their values and preferences regarding treatment is essential for providing quality, person-centred care, specific to individual needs. Regardless of the model of care utilised, this study highlights that changes to SCS in cancer is required to better meet the needs of rural men.

Conclusion

Cancer has physical and psychosocial implications for men that extend to their masculine identity and may force them to renegotiate their constructions of themselves. Physical issues appear to overlap with gender issues, whereby the impact of loss of income, physical discomfort and changed intimate roles were found in this study to be linked to masculine ideals. Men that identify with more traditional gendered roles therefore may be impacted by cancer more profoundly than women — this may be particularly true in rural settings. This study showed that rural men with cancer have unmet needs. Although the SCS captures the domains of physical, emotional, family and spiritual/religious concerns, it does not capture the patients' understanding of these aspects in a formal way or help to tailor learning needs.

Research impact

This study highlights the importance of ongoing evaluation of service delivery, in particular the importance of consumer perspectives of outcomes of the quality of care.

Indirectly, the rural ambulatory cancer service employed a prostate cancer nurse following this study. The results were able to inform how the service could tailor care provisions to the unmet needs of men with cancer, including the implementation of a support group.

Ethical approval

Ethics approval to conduct the study was granted by the Goulburn Valley Health Human Research Ethics Committee (approval number HREC/GVH44/15).

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Competing interests

The authors declare that they have no competing interests.

Consent for publication

All focus group participants were over the age of 18 years and gave written consent for participation. The consent form clearly states the intention to publish findings of the study.

Authors' contributions

CO and HH collected data. CO and KE analysed the transcripts. KE wrote the first draft, CO, HH, AK and LJ contributed to subsequent drafts. All authors read and approved the final manuscript.

Availability of data

De-identified transcripts of the focus groups and field notes are available from the corresponding author.

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Nurses self-reporting and impression of compliance to chemotherapy administration safety standards and patient assessments: a multi-institute survey of oncology nurses in the Emirate of Abu Dhabi

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Abstract

Introduction Professional nurse education is required to ensure a safe level of care for individuals receiving chemotherapy.

Aim The aim of this study was to measure registered nurses' self-reported impression of compliance with the chemotherapy administration standards expected of them.

Method A quantitative method with an online survey of 22 questions asking nurses their perceived compliance to chemotherapy administration standards was utilised.

Results The results showed that the majority of nurses state that they are confident to correctly administer chemotherapy; some nurses admitted to not adhering to safe practices all of the time.

Practice implications Appropriate education and demonstration of competency does not make nurses compliant and practice should be audited to ensure compliance with safe administration practices.

Conclusion Further analysis of methods to ensure nurses and patients are safe during chemotherapy administration is warranted, thus improving patient outcomes and experiences.

Introduction

The administration of chemotherapy is a high-risk practice which entails numerous risk factors with a high error index[1]. To ensure patient safety, nurses must receive appropriate education on chemotherapy drug administration[2], attain expert knowledge, and achieve competencies and skills prior to administering chemotherapy[3]. Competence in chemotherapy administration consists of specialised education and preparation, consisting of didactic learning followed by successful completion of a clinical practicum[4]. Standards of practice provide guidelines for education and safety, ensuring nurses have the essential knowledge to administer chemotherapy in a way that is safe for both the patient and the nurse[5].

Background

In the Emirate of Abu Dhabi, United Arab Emirates (UAE) nurses administer chemotherapy to adult and paediatric oncology patients in three major tertiary facilities. At the time of this study, each facility had a different method of providing appropriate education and undertaking competencies for the safe practice of administering chemotherapy. In 2016, Abu Dhabi Health Services (SEHA) had a growing need for skilled speciality nurses due to difficulties in recruiting nurses with specialised skills. Identified nursing speciality areas established nursing advisory groups (NAG) comprising executive nursing leads, clinical nursing experts and clinical educators with nurses from each of the business entities (BEs) within their speciality involved. Establishing the NAG was critical in defining minimum standards of education and competency as well as recommending use of or developing appropriate methods to upskill a competent nursing workforce with the required skills. Oncology was identified as one of those specialities.

The initial step towards standardising education and competency for oncology nurses was to establish the nurses' self-reported confidence and compliance with the Oncology Nursing Society Standards of Chemotherapy Administration. It was known that each hospital delivered theoretical knowledge and clinical assessment differently. The chief nursing officers of each hospital requested cost-effective, evidence-based education. The next step was to scope the best resources available to develop a comprehensive and evidence-based oncology nursing education program. This article will report on the results of a survey undertaken in the initial phase of the standardisation of oncology nursing education in SEHA and discuss the current evidence on the effectiveness of some of the literature discussing oncology education programs and compliance with the ASCO/ONS standards.

Aim

The aim of this survey was to measure the self-reported impression of compliance with the existing chemotherapy administration standards expected of them in SEHA by registered nurses working in tertiary care facilities departments. Secondly, we wanted to highlight areas for improvement on compliance and self-reported confidence, which would be integral when developing a standardised educational oncology nursing program for SEHA.

Methodology and design

A quantitative method was utilised with an online survey using a Likert Scale (1 being the lowest and 5 being the highest). A review of the literature was undertaken in February 2015 by the author (WH), using the keywords "chemotherapy; standards; guidelines; rules; oncology nurse; scope of practice" in SEHA e-library database, Google scholar and EBSCOhost. The inclusion criteria were set for all full articles from 2010 to 2016, which was then expanded to 2009 to 2016, as the number of articles was low, articles written in English and with a focus on the nursing-related standards. A total of 11 articles were chosen and reviewed to reflect on the effect of the application of standards on nursing practice and its effect on the quality of care provided.

Ethics approval

Ethics approval was obtained from the Tawam Hospital Nursing Research Committee, which was then required to be submitted to the Al Ain Medical District Human Research Ethics Committee (AAMDHREC). Approval was granted to conduct the study of oncology nurses from three SEHA facilities.

The survey

A qualitative cross sectional survey study completed in South Korea by Kidong Kim and colleagues[1], aimed to measure nurses' adherence with the chemotherapy standards in a Korean Cancer Care Centre. It used a 16-question survey covering different standards. It was this study that prompted the author (WH) to ask if a similar study had been undertaken in the UAE.

The Oncology Clinical Resource Nurses from the Oncology Haematology NAG felt that it was a very important survey to ask and would assist in determining the nurses' level of confidence in being able to provide clinical care aligned with well-established American Society of Clinical Oncology/Oncology Nursing Society Chemotherapy Administration Safety Standards, Including Standards for Pediatric Oncology. This would be of particular interest to the senior oncology nurses working in the three tertiary hospitals as little was known about the guideline adherence of nurses to chemotherapy administration guidelines. Each hospital had their own policy/guideline and theoretical knowledge and clinical competency was attained using different resources.

Permission was obtained from Kidong Kim to use a modified version of the original questionnaire from his previous survey "Guideline adherence to chemotherapy administration safety standards: a survey on nurses in a single institute"[1]. The original 16 questions were used with additional detailed questions for the purpose of our study, resulting in 22 questions, which sought to gain knowledge about the nurses' years of oncology experience in the UAE and their home country (Appendix 1). It also sought information on the type of assessments required and level of confidence in practice. The survey was sent via SurveyMonkey to all 118 nurses' SEHA email addresses, working in the oncology departments in three hospitals in the Emirate of Abu Dhabi.

Appendix 1: The survey questions (adapted with permission from Kim et al., 2011)

1. Which BE (hospital) are you working in?
2. In which country did you study to become a registered nurse?
3. What year did you graduate?
4. How long have you been working in oncology/haematology?
   a. Less than 12 months.
   b. 1–2 years.
   c. 2–3 years.
   d. 3–4 years.
   e. 4–5 years.
   f. 5 years or more.
5. Were you working in oncology / haematology in your home country?
   a. Yes.
   b. No.
6. How long have you been working in oncology nursing in the UAE?
   a. Less than 1 year.
   b. Less than 2 years.
   c. Less than 5 years.
   d. 5–10 years.
   e. 10 years or more.
7. In your current job, are you required to administer chemotherapy?
   a. Yes.
   b. No. Thank you. You have finished the survey.

8. In your current role as a chemotherapy nurse, are you required to complete a theoretical assessment?
   a. Yes.
   b. No. Thank you. Please go to question 12.
9. What kind of theoretical assessment is required in the BE that you are working in?
   a. Reading the policies and procedures of my BE.
   b. Self-directed learning provided by my BE.
   c. Online learning, e.g., ONS chemotherapy and biotherapy course or an equivalent.
   d. Lippincott Procedures online.
   e. There is no theory requirement in my BE to administer chemotherapy.
10. How often do you have to complete the theoretical assessment?
   a. Once only.
   b. Annually.
   c. Every 2 years.
11. When did you last complete your theoretical assessment?
   a. In the last 12 months.
   b. In the last 2 years.
   c. I only had to do the theoretical assessment once.
12. In your current role as a chemotherapy nurse, are you required to complete a clinical assessment for administering chemotherapy?
   a. Yes.
   b. No. Thank you. Please go to question 14.
13. How often do you have to complete a clinical assessment for administering chemotherapy?
   a. Once only.
   b. Every year.
   c. Every 2 years.
14. Thinking about your own clinical practice when administering chemotherapy, please chose an answer (always; usually; sometimes; never; N/A) to the following questions:
   a. I check the height and weight of the patient at every cycle.
   b. I look for a valid consent before administering chemotherapy.
   c. When orders vary from standard regimens, I request confirmation of the order by physicians.
   d. When laboratory parameters are abnormal, I request confirmation to proceed from the physician.
   e. I do not take verbal orders, except to hold or stop the administration of chemotherapy.
   f. Before administration of chemotherapy, two chemo-competent nurses verify the patient's name, medical record number, drug name, dose, route, volume, expiration dates/times, sequence, appearance and physical integrity, and sign to verify this was done.
   g. When a medication is packed in a light-sensitive cover, I confirm the identity of the labels inside and outside of the cover.
   h. When I am working with intrathecal and intravenous chemotherapy, I bring the intrathecal and intravenous chemotherapy to the patient separately.
   i. The chemotherapy medication label includes the patient's name and medical record number, drug name, route of administration, dose, volume, date of administration, date and time of preparation and expiration.
   j. I check that the intrathecal medication is labelled with a uniquely identifiable label.
   k. When handling chemotherapy and related waste products, I wear all the required PPE as per the policy in my BE.
   l. Chemotherapy is administered using a closed system all the time in my BE.
15. For the following questions, please consider your level of competence (expert; proficient; competent; advanced beginner; novice; never done this before) to manage these clinical scenarios:
   a. Cleaning up a chemotherapy spill.
   b. Managing an adverse reaction to chemotherapy.
   c. Managing an extravasation.
   d. Providing education to the patient and family about possible side effects.
   e. Performing pre-chemotherapy patient assessments.
16. Chemotherapy orders in my BE are handwritten on paper.
   a. Yes.
   b. No.
17. Chemotherapy orders in my BE are preprinted but with some parts of the prescription handwritten.
   a. Yes.
   b. No.
18. Chemotherapy orders in my BE are electronically generated in Malaffi in my BE.
   a. Yes.
   b. No.
19. All chemotherapy prescriptions must be signed by a consultant/specialist physician.

a. Yes.
b. No.
c. Not sure.

20. On a scale from 1 (extremely low) to 5 (extremely high) thinking about my clinical practice I am confident that the theory and clinical components provided by my BE have prepared me to be a safe oncology nurse.
    a. Theory assessment was adequate.
    b. Clinical assessment was appropriate.
    c. Policy is clear and easy to understand.
21. In my BE I am aware that my clinical practice is regularly observed and checked for compliance to policy and my application of evidence-based nursing.
    a. Yes.
    b. No.
    c. Unsure.
22. I believe that regular feedback of my practice of administering chemotherapy would help me be a more reflective practitioner, and encourage me to check my own practice regularly.
    a. Yes.
    b. No.
    c. Unsure.

UAE survey results

A total number of 118 invitations for the survey were sent on October 2015, one reminder was sent to each group through email. Of the 118 invitations, 51 were returned but only 44 were fully completed, a return rate of 37.2%. The three participating hospitals had varying response rates. Hospital A had a 64.71% participation rate, of which 46.26% was completed, whereas hospital B had 29.41% participation rate and hospital C had only 5.88% completed, of which only one response was fully completed.

The results reflected on the hospitals' competency assessment process and their nurses' level of confidence after undertaking these assessments. Although not standardised, all participating hospitals have a theoretical component; hospital A uses the Oncology Nursing Society Chemotherapy and Biotherapy online course, whereas hospital B used hospital policies and procedures and an in-house oncology course and hospital C used the *Lippincott® Nursing Procedure Manual*. Inconsistencies existed regarding the frequency of theoretical and clinical assessment; nonetheless all three hospitals required annual clinical assessments. It is worth mentioning here that some staff from the same hospital did not appear to know the frequency of the competencies.

Analysis of the data was undertaken by the author (WH) by reviewing each question and summarising the data into graphs. The nurses came from the Philippines (62.75%), India (13.73%), Jordan (7.84%) and the UAE (5.88%) and the majority graduated after 2000 (43.13%), the next largest group was 35% who graduated between 1991 and 2000 (Table 1). Reviewing the years of experience and whether the nurses had any prior oncology experience, results showed the majority of the surveyed staff (74.51%) had more than five years of experience in oncology and 20 (41.67%) had worked in oncology prior to coming to the UAE. When asked about their level of confidence, the majority 52.59% answered "extremely confident", and 47.41% answered "confident" (Table 2).

Table 1: Demographics of respondents

Country studied as RN	
Philippines	32 (62.75%)
India	7 (13.73%)
Jordan	4 (7.84%
United Arab Emirates	3 (5.88%)
Year graduated	
1971 – 1980	3
1981 – 1990	8
1991 – 2000	18
2001 – 2011	22

When asked a series of 12 questions about the steps taken before administering chemotherapy, aligned with the ONS standards, 97.64% chose "Always" as their answer to the administration and handling standards. This was followed by 1.47% who answered "Usually" to some of the questions concerning height and weight checking, taking of verbal orders, double checking with the ordering physician in case of variation from the regimen and administering chemotherapy in a closed system.

It was noted that some of those who had less experience in the UAE, but still with a total of more than five years were not exposed to any chemotherapy spillage or extravasation situations and answered the related questions as "haven't experienced this before". And that resulted in them choosing a lower level of confidence (3–4) when asked to choose their level of confidence that the theoretical and clinical assessment provided by their facility prepares them to be a safe practitioner (1 is the lowest and 5 is highest). Furthermore, when asked about specific clinical scenarios, 43.91% across all hospitals deemed themselves as experts, 30.86% as competent and 18.26% as proficient (Table 3).

For the question about whether chemotherapy orders are handwritten, preprinted and filled by hand or electronically signed, 97.78% of respondents replied that chemotherapy orders are preprinted on a template, completed by hand and 100% confirmed the order is placed by a consultant/specialist physician. This is noteworthy because it is known that one hospital uses both a preprinted and electronic order. The 2016 Updated American Society of Clinical Oncology/Oncology Nursing Society Chemotherapy Administration Safety Standards,

Table 2: Level of confidence in preparedness to be a safe oncology nurse (45 respondents; 6 skipped) Note: BE = business entity (hospital)

On a scale from 1 (extremely low) to 5 (extremely high) thinking about my clinical practice I am confident that the theory and clinical components provided by my BE have prepared me to be a safe oncology nurse	**1**	**2**	**3**	**4**	**5**	**Weighted average**
Theory assessment was adequate	4.44% N=2	2.22% N=1	13.33% N=6	28.89% N=13	51.11% N=23	4.20
Clinical assessment was adequate	4.44% N=2	0.00% N=0	15.56% N=7	28.89% N=13	51.11% N=23	4.22
Policy is clear and easy to understand	4.44% N=2	0.00% N=0	13.33% N=6	26.67% N=12	55.56% N=25	4.29

Including Standards for Pediatric Oncology states that when ordering, preparing, dispensing and administering chemotherapy, "the health care setting uses standardised, regimen level, preprinted or electronic forms for parenteral chemotherapy”[5].

The use of paper prescriptions has been demonstrated to be a source of chemotherapy medication errors[6]. Ranchon and colleagues showed in their prospective study in France that 91% (408/449 errors) of chemotherapy medication errors concerned inadequate prescriptions. Additionally, the study performed a cost analysis of medication errors linking them to increased costs of new potential hospitalisation, prolonged hospitalisation and additional drug costs[6]. The study concluded that electronic prescribing of antineoplastic chemotherapy is the next step in the ongoing process of improving safety. Among the 449 medication errors, 436 were intercepted by physicians, pharmacists, or nurses prior to administration, while 13 reached the patients (2.9% of all errors), demonstrating that nurses’ knowledge and competency is integral to reducing harm when chemotherapy orders are written on paper. Electronic prescribing was possible in the electronic medical records and medication management system in the UAE, but there was reluctance to utilise it due to concern of its safety.

The literature

Much of the literature discusses the implementation and practice changes to comply with the ASCO/ONS Chemotherapy Administration Safety Standards that were first published in 2009 and have been periodically reviewed and updated[4,5,7-10]. This is not surprising as they have transformed the safety of administering cancer drugs ever since.

The ASCO/ONS standards are divided into: staffing-related standards, chemotherapy planning standards, chemotherapy ordering, general practice and administration-related standards (which includes drug preparation, patient education and consent, drug administration, monitoring and assessment). An elaboration on the standards of general practice and administration will be discussed later as it is the part applicable to the research from a nursing perspective.

To ensure safe chemotherapy treatment throughout all phases involved in the prescribing, preparation and administration of any type of chemotherapy drug health care workers are required to achieve speciality qualifications. This includes requirements such as only a licensed independent practitioner who is qualified according to the practice policies and guidelines

Table 3: Nursing skills that are assessed as part of the annual competency

Skill	**Expert**	**Proficient**	**Competent**	**Advanced beginner**	**Novice**	**Never done this before**	**Total**	**Weighted average**
Cleaning up a chemotherapy spill	11 23.91%	8 17.39%	20 43.48%	2 4.35%	2 4.35%	3 6.52%	46	2.57
Managing an adverse reaction to chemotherapy	25 54.35%	6 13.04%	13 28.26%	2 4.35%	0 0.00%	0 0.00%	46	1.83
Managing an extravasation	12 26.09%	10 21.74%	17 36.96%	4 8.70%	0 0.00%	3 6.52%	46	2.48
Providing education to the patient and family	27 58.70%	8 17.39%	11 23.91%	0 0.00%	0 0.00%	0 0.00%	46	1.65
Performing pre-chemo patient assessments	26 56.52%	10 21.74%	10 21.74%	0 0.00%	0 0.00%	0 0.00%	46	1.65

can write the order and these orders can only be prepared by a pharmacist, pharmacy technician, or nurse determined to be qualified according to the practice's policies and guidelines. Administration must be by "qualified physicians, physician assistants, advanced practice nurses, or registered nurses"[7]. All new oncology nursing staff employed in the three hospitals treating cancer patients in Abu Dhabi must complete core mandatory competencies for the administering and monitoring of chemotherapy that are renewed annually.

Nurses are recommended to comply with ASCO/ONS Chemotherapy Administration Safety Standards prior to administering any of the medications[4,5,7]. Standards serve as foundation for best practice, can reduce the risk of errors, increase efficiency and provide a framework for best practice, improve patient outcomes and reduce harm[7,8]. Poor adherence to the guidelines and standards has been found to impact the success and safety of treatment[7] and adherence to treatment guidelines prior to 2014 can be as low as 60% in countries such as the United States of America (USA) due to a range of complex issues[8].

Schleisman and McMahon[11] describe in a case study how easy it is for medication errors to occur when administering oral chemotherapy when all of the guidelines and best practices are not adhered to. It has been identified that many USA cancer centres have fewer safety standards for oral chemotherapy compared to intravenous chemotherapy. Establishing standards and implementing safety systems for oral chemotherapy can reduce prescribing error risk by 69% through eliminating errors that can lead to significant patient harm[12]. Weingart *et al.*[10] sought to assess the implementation of ASCO/ONS standards in an effort to demonstrate the extent of compliance to the standards in 44 National Cancer Institute centres in the USA. Implementation varied dramatically, with only four centres reporting full implementation of all 31 standards.

This can be seen also in the original study conducted by Kim *et al.*[1], which highlighted a weakness in double-checking of chemotherapy prior to administration and lack of clear competency checking for nurses. Twenty-nine per cent of the respondents did not conduct routine bedside double-checking and only 45% of the respondents reported the presence of a standard competency monitoring in their facility. The study was conducted to gain insight into the nurses' level of confidence in assessing patients in preparation for administration of chemotherapy, looking to find correlation with length of experience and theoretical education and seeking areas to improve nursing practice in relation to chemotherapy practices.

Guidelines developed by professional practice organisations and government agencies for the safe handling of hazardous antineoplastic drugs have been available for three decades. Since the mid-1980s, several surveys of nurses have been conducted to evaluate use of personal protective equipment (PPE) and other exposure control measures during compounding activities. Each of these studies reported on the use of gloves and gowns, with only periodic reporting on specialised training[13]. Incidents continue to occur even when standards are introduced, and electronic systems are in place aimed at minimising errors[14,15].

Other countries have also published oncology nurse standards and competencies for the safe practices of administering and caring for patients receiving chemotherapy: the Canadian Association of Nurses in Oncology (CANO) and the Clinical Oncological Society of Australia (COSA). The ASCO/ONS guidelines are not applied internationally everywhere, although they are cited in many guidelines.

The CANO standards specifically describe the role of registered nurses and their scope of practice, as well as the psychological aspect of assessment, the "emotional, cultural, and spiritual context", which includes any fear, ability to cope, need for language assistance and any other issues identified by the patient[16]. Similar standards were elaborated in the report and steps were mentioned to help practitioners apply those standards[16]. Also, another aspect that was paid special attention from the CANO is nursing competencies, a holistic educational program that covers different aspects from cell aetiology to safe administration and assessment; reflecting the practice standards for nurses was developed in Newfoundland and Labrador, it helped nurses gain the proper knowledge and skills to handle the advanced practice of being an oncology nurse. O'Leary[17] considered the education integral as an initiative to improve nursing practice and align the education and care with the standards.

Similarly, the Clinical Oncology Society of Australia (COSA) guidelines are concerned with the prescribing, dispensing and administration of chemotherapy agents, elaborating on the role of each health care provider in these stages. These were found to be consistent with the ASCO/ONS standards. The COSA guidelines for nurses regarding the administration phase also highlighted the importance of core competency and basic knowledge for nurses when it comes to different clinical situations, particularly in the event of emergency or adverse effects. COSA states what is acceptable to properly administer the medications and what monitoring and assessment should be done prior and after the administration. They also mentioned the checklist that should be followed and how it should be compatible with protocol and policies[7,18].

A quasi-experimental research study by Al-Magid and colleagues[3] sought to elicit the opinions of health care professionals (nurses and physicians) at Assiut University Hospitals in Egypt, the basic competencies required to provide care to cancer patients receiving chemotherapy. They found that nurses' knowledge and application of their standards increased after one month and increased again after three months of implementation of the agreed standards, in regard to the experience factor and its effect on nurses' confidence in practice. This study looked at the demographic data of the nurses and their knowledge and practice in the oncology setting. It identified that the mean and standard deviation (SD) of oncology nurses' knowledge are higher at age (<20 years), higher in those who attended a nursing technical institute or attained a bachelor than a diploma and in regard to years of experience, the mean and SD of oncology nurses' knowledge are higher at (1–<5 years). The higher knowledge in the youngest age group was linked to higher tertiary education qualifications than their senior counterparts.

In a prospective, comparative, mixed-methods study by Colvin and colleagues[19], who sought to compare objective and subjective nurse behaviours of expected safe chemotherapy handling, they discovered that nurses' observed practice did not always align with their subjective statements. Specifically, self-assessed adherence to PPE and safe handling policies ranged from 17% to 92% and in some cases the use of absorbent pads during the administration of chemotherapy was self-reported as 83% compliant but observed to be adhered to only 8% of the time. The authors concluded that knowledge about observed and self-assessed adherence to safe practices may require more than annual competency assessments; this may not be unique to the safe handling, but in fact to the many other safe practices that are outlined in standards for safe handling and administration of chemotherapy.

Discussion

The nurses in this study answered 100% that they were aware that their clinical practice is regularly observed and checked for compliance to policy, and they were equally certain that regular feedback of their practice administering chemotherapy would help them be a more reflective practitioner and encourage them to regularly check their practice.

It is established that patient assessment prior to the administration of chemotherapy is paramount to patient safety[5,7]. The nurses in this study stated that 95.65% of the time they would 'always' check the height and weight of the patient at every cycle of chemotherapy and 4.35% of the time they 'usually' check the height and weight. When asked if they 'look for a valid consent before administering chemotherapy' and 'when laboratory parameters are abnormal' they request confirmation to proceed from the physician, the response was 100% of the time as it was for the question if they completed all of the patient chemotherapy medication safety checks and confirm completion with a signature.

Responses to two other questions that address patient safety were interesting. That is, when a medication is packed in a light-sensitive cover, 97.83% of the respondents said that they would confirm the drug by checking the labels, both inside and outside the light-sensitive bags, and 93.48% of the respondents said that they do not take verbal orders, except to hold or stop the administration of chemotherapy. Interestingly, those nurses that answered 'usually' to questions about height and weight, wearing PPE when handling chemotherapy, the acceptance of verbal orders and obtaining physician confirmation if orders vary from the standard were all nurses who had undertaken the ONS Chemotherapy Biotherapy Course. The ONS Chemotherapy Biotherapy Course was being considered as the benchmark for the theoretical component for competency. Nurses must practise at a competent level, and certification is one method available for competency assessment[20].

A prospective, descriptive study by Coleman and colleagues, aimed at comparing certified ONS nurses with non-certified nurses, tested the hypothesis that compared to non-certified nurses, certified nurses would have greater knowledge and clinical behaviours and outcomes for management of pain and chemotherapy-induced nausea and vomiting (CINV)[20]. The results provide some support to the hypothesis that certification improves patient care quality, but they conclude the impact on patient outcomes needs continued exploration.

Questions about safety with intrathecal chemotherapy were skewed due to misunderstanding reading the question. English is not the first language for any of the nurses responding to the survey, although ability to speak and read English is a requirement for working in the health system of Abu Dhabi. All documentation in electronic medical records must be in English. It would have been difficult to have the survey in many languages.

Conclusion

The results of our survey showed that all SEHA facilities mandate a pre-assessment, although this is not standardised, and the nurses' knowledge of the standards and their level of confidence rise with their years of experience and exposure to chemotherapy-related practice. Relying on self-reporting of compliance and confidence may not provide indication of the true skill and compliance to standards. Publications are beginning to note translation of the standards into practice[9,10], seeking to demonstrate compliance to safe practices and more recently in quaternary care medical oncology centres, nurses have not complied to all of the best practices when administering chemotherapy[19]. Therefore, education is but one aspect of the process; policy and standards must be in place and speciality health professionals are integral to patient safety, since we all seek to practise and provide cancer care from the best evidence. Another strategy recommended is that cancer centres and oncology practices should be audited to ensure compliance with safe administration practices[14].

The next question must be: what education is required and does certification through a recognised professional body assist? Literature has focused on the importance of having specialised oncology nurses who have completed additional courses and educations regarding management of cancer patients and highlighted the effect it has on patient outcomes. As highlighted by Coleman and colleagues[20], certification can improve patient outcomes but the impact needs further exploration.

Implications for practice

There is a lack of literature in the Middle East regarding the expected standards and educational requirements for oncology nurses administering chemotherapy. Further review and standardisation of SEHA policy are recommended. Education and competency assessments ensuring nurses administering chemotherapy have the necessary skills in oncology care is warranted. Research into the outcomes, specifically nursing-sensitive outcomes of the education program developed and compliance to safe practices will add to the small number of studies in this area.

Limitations

Limitations existed in this study. This study only sought self-reported data and thus has limited ability to critique reasons for the nurses' responses and events affecting non-compliance to the guidelines. Further research to compare perceived and actual behaviours by individual nurses may provide a better understanding of those events leading to non-compliance.

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Conflict of interest

The authors declare no potential conflicts of interest.

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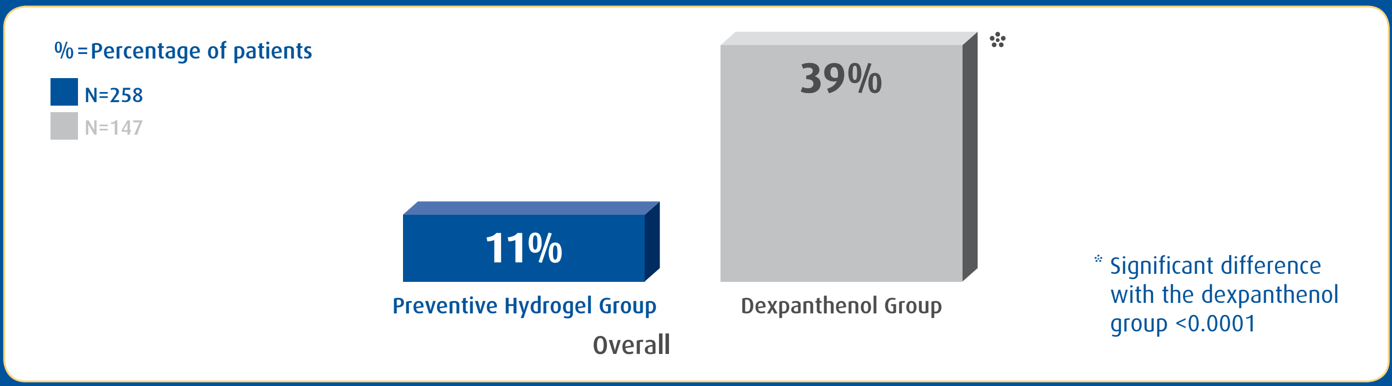

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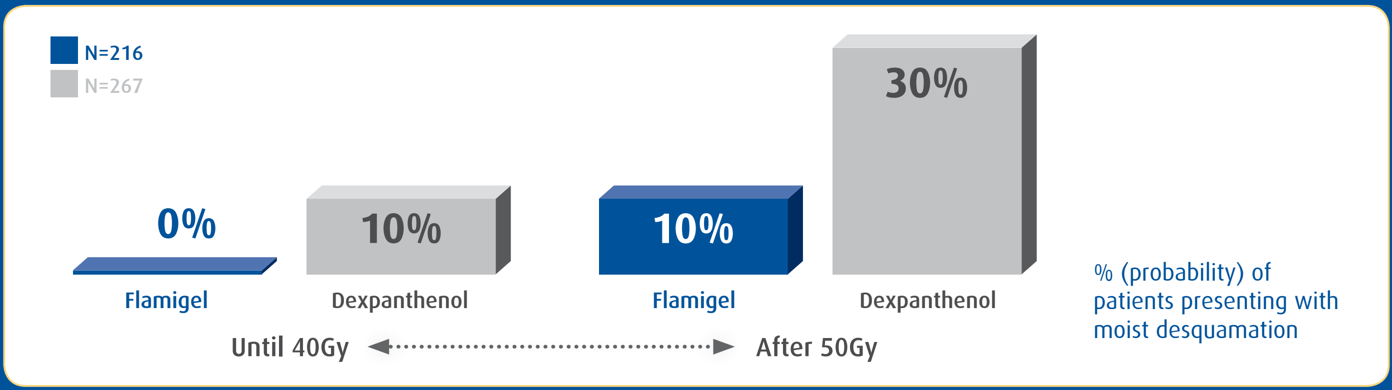

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