The Australian Journal of Cancer Nursing

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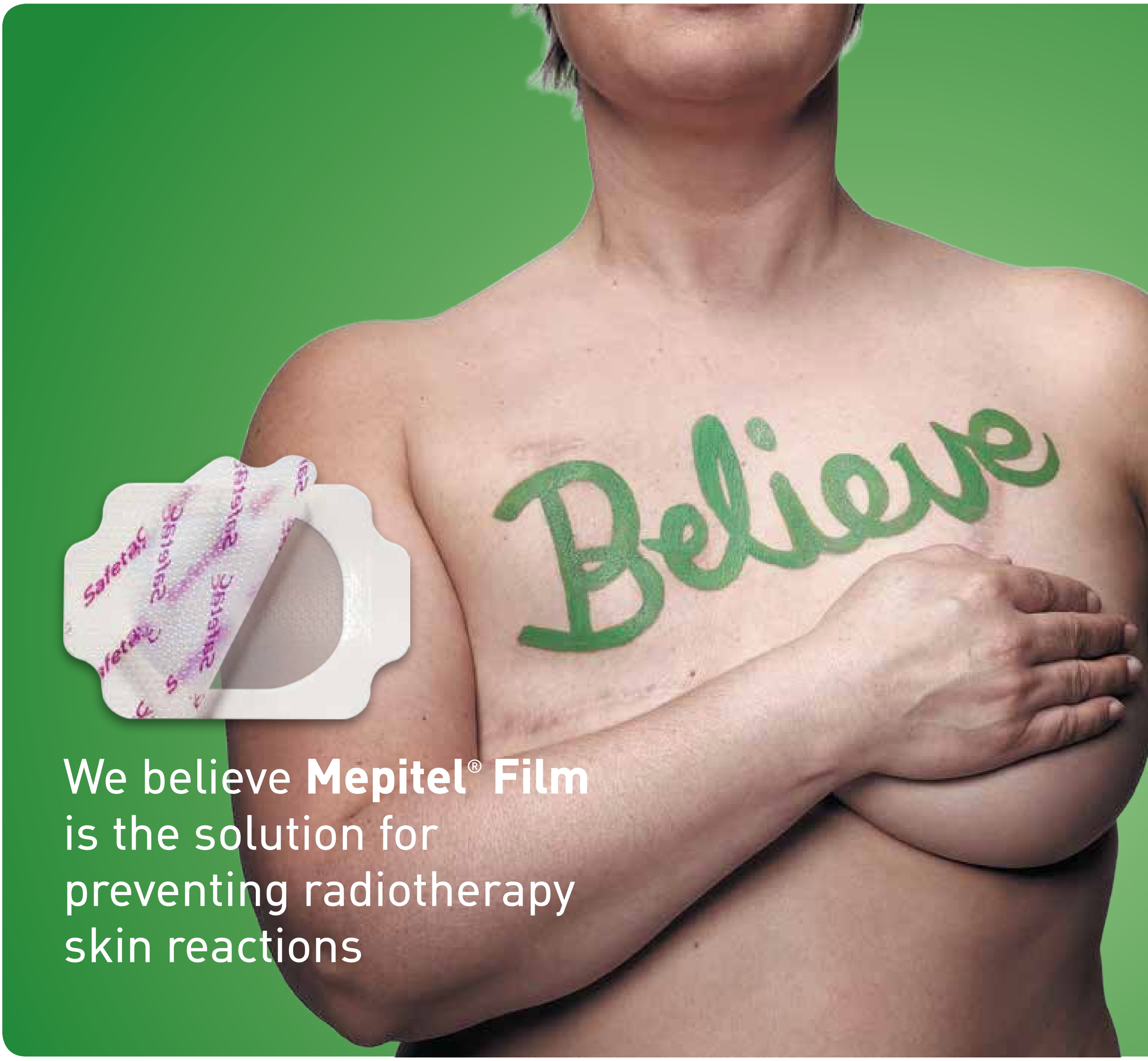
In this issue



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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.

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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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Letitia Lancaster RN, Onc Cert, BHSc (Nsng), FACN
Clinical Nurse Consultant Gynaecological Oncology, Westmead Hospital, Westmead NSW 2145
Tel (02) 9845 5555 page 08503 Fax (02) 9845 8311 Email Letitia.Lancaster@health.nsw.gov.au

Moira Stephens RN, PhD, MSc, BSc (Hons), Grad Cert (Cancer Nursing), Grad Cert (HIV/AIDS Nursing), Grad Cert (Teaching & Learning in Higher Education)
Senior Lecturer, School of Nursing, Faculty of Science, Medicine and Health,
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PUBLISHING
A division of Cambridge Media
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Editorial

Much to celebrate, but we need to do more

Letitia Lancaster • RN, Onc Cert, BHlthSc (Nsng), FACN
Clinical Nurse Consultant, Gynaecological Oncology, Westmead Hospital, Westmead, NSW

As CNSA approaches its 18th Winter Congress and third year as an independent organisation, we have a robust society with much to celebrate:

- a membership of over 1,000 cancer nurses across Australia (and some from New Zealand)
- sound governance structures
- vibrant committees, Regional Groups and Specialist Practice Networks that promote extended networking and professional development activities
- a voice in national and international policy development and cancer control activities
- recognition as a peak professional body and formal affiliations with COSA, Cancer Australia, the Coalition of National Nursing Organisations, the International Society of Nurses in Cancer Care, Cancer Council Australia and the Union for International Cancer Control.

The papers featured in this issue of *AJCN*, however, highlight opportunities for improvement in the provision of cancer care, particularly for some of our most vulnerable individuals. The first two papers (Meiklejohn *et al.* and Ryan *et al.*) were invited for publication following sobering plenary presentations at last year's Winter Congress; Gail Garvey talked about cancer care in Indigenous communities and Kim Ryan about improving the whole patient journey through improved mental health care.

Compared to other Australians, Indigenous Australians have higher cancer mortality rates because they are: less likely to participate in screening programs; more likely to be diagnosed with preventable cancers (lung, cervix, uterus and liver); and more likely to present with more advanced disease at diagnosis[1]. The reasons for this are political, social, cultural, multifactorial and complex. They include, but are not limited to, geographical remoteness, economic disadvantage, social exclusion, a higher burden of concurrent chronic diseases, cultural perceptions of cancer and a distrust of mainstream health services[2,3]. The paper by Meiklejohn and colleagues describes the perspectives of tertiary health professionals when providing cancer care to Indigenous patients and highlights some of the shortcomings of both the health system and the staff in providing culturally competent care. This very important aspect of cancer care is one which we must all strive to understand better.

Approximately one-third of people with cancer in acute-care settings will present with a concurrent mental health condition[4]. Additionally, many other cancer patients will experience various levels of psychological distress during their illness trajectory. In the busy clinical environments in which we work it can sometimes seem overwhelming for nurses to formally address these issues on top of the provision of complex physical care. Kim Ryan and colleagues from the Australian College of Mental Health Nurses (ACMHN) present a clear argument in their paper that the provision of psychological care begins with empathy, kindness and being genuine, and this is indeed the domain of every nurse. They also highlight some potential concerns with specialisation and sub-specialisation in nursing (as many of us have chosen to do) and that is focusing on the specific disease (in our case, cancer) and how it affects the patient and family, with less attention being paid to an in-depth understanding of their concurrent medical problems. While we increasingly focus on specialist care, we can't fully address the needs of the patient and their family until we take a person-centred approach. These matters are addressed in a series of eLearning modules, *Enhancing the Patient Journey* (http://www.acmhn.org/component/content/article?id=394:all-elearning-modules), developed by ACMHN in collaboration with other nursing organisations, including CNSA. I highly recommend the program for *all* cancer nurses as a means of improving our understanding and early identification of mental health issues that often go hand-in-hand with living with chronic disease.

The Cancer Council Helpline has been well-established entity in all states and territories in Australia for more than 20 years and a valuable resource for both the lay public and health professionals. It provides a unique service in that it is staffed by oncology-trained personnel and offers a different type of support than that provided by clinically based services or consumer groups. The study by Boltong and colleagues, however, describes a declining use of the Helpline over the last five years, despite an increasing cancer incidence in Australia. A number of reasons for this trend have been suggested, including the increasing use of web-based information and support. Importantly, and of concern to us, is that while 51% of respondents said that they would call the Helpline if recommended by a clinician, only 4% recall having a clinician recommend the Helpline. Furthermore, of those who had used the Helpline, only 5% said that it had been recommended by a nurse. We have a responsibility as cancer nurses to provide patients and their families with information about a variety of support options available to them. One size does not fit all and it is presumptuous for us to assume that the information and support provided by clinicians is all-encompassing or in fact completely understood.

The final paper by Condon and colleagues provides an excellent overview of, and management strategies for, the unique and distressing side effects related to epidermal growth factor inhibitors. While these distinctive side effects are not a feature of conventional chemotherapy and may therefore be less familiar to cancer nurses, they can have a significant impact on the patient's quality of life. Early recognition and management is inherent upon diligent nursing assessment, patient education and support in the same way that we do for toxicities with which we are very familiar such as mucositis, and nausea and vomiting. It is imperative that we avail ourselves to educational opportunities (including this paper) to gain an in-depth understanding of the side effect profiles of new drugs.

The theme of this year's Winter Congress is *Cancer Nursing: Expanding the Possibilities*. All four papers in this issue of *AJCN* highlight aspects of cancer nursing practice where there is room for us all to expand the possibilities in the care that we provide.

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Indigenous cancer care in Queensland, Australia: health professionals' framing of "difference"

Judith A Meiklejohn* • Research Assistant, Cancer Epidemiology, Menzies School of Health Research, Brisbane, QLD
PO Box 10639, Brisbane Adelaide Street, Brisbane, Qld 4000
Email: Judith.meiklejohn@menzies.edu.au Tel: (07) 3169 4223

Jon Adams • Professor of Public Health & ARC Professorial Future Fellow, Faculty of Health, University of Technology, Sydney, NSW

Patricia C Valery • Associate Professor; Head, Cancer Epidemiology Group; Menzies School of Health Research, Brisbane, QLD

Euan T Walpole • Medical Director — Division of Cancer Services, Princess Alexandra Hospital, Brisbane, QLD; Cancer Stream Leader — Metro South Health and Hospital Service; Associate Professor of Medicine, University of Queensland, Brisbane, QLD

Jenny H Martin • Chair of Clinical Pharmacology, University of Newcastle School of Medicine and Public Health, Callaghan, NSW; Southside Clinical School, University of Queensland, Brisbane, QLD

Hayley M Williams • Research Assistant, Cancer Epidemiology, Menzies School of Health Research, Brisbane, QLD

Gail Garvey • Division Leader of Epidemiology and Health Systems, Menzies School of Health Research, Brisbane, QLD

*Corresponding author

Abstract

This paper reports on interviews with tertiary health professionals to elicit their perspectives of Indigenous cancer patients and report on factors influencing clinical decisions, particularly concerning co-morbidities, Indigeneity, and access and use of cancer services. The overarching concept of "difference" framed three main categories: "Acknowledging difference", "Not knowing how to accommodate difference" and "Not seeing difference". Findings indicate some health professionals acknowledge and aim to address needs and expectations of Indigenous cancer patients; however, challenges in identifying Indigenous status, limitations in providing relevant care within a biomedical system, and outdated assumptions and constraints of the health system limit this endeavour. Consistent and accurate recording of Indigenous status in medical records is important for health professionals to identify Indigenous status in a sensitive and timely manner. Cultural competence training should be embedded within all health training and be part of ongoing systematic organisational processes to improve the provision of culturally appropriate cancer care.

Keywords Indigenous; cancer; qualitative; cancer care.

Introduction

Cancer is a leading cause of health disparity between Indigenous and non-Indigenous Australians. Significant differences in cancer mortality and survival have been well reported[1-3] and whilst not fully explained, later diagnosis, higher rates of comorbidities, and reduced uptake of and access to cancer services have been reported as contributing to these poorer outcomes[4,5]. However, disparities in cancer treatment are reported as accounting for most of the survival deficit amongst Indigenous Australians[6].

As highlighted in recent studies, the reasons for why Indigenous Australians receive less cancer treatment (chemotherapy, radiotherapy and surgery) are multifactorial. These include individual-level factors, such as Indigenous people's lack of familiarity with the hospital system, feelings of isolation, distrust and fear of the biomedical system[7-10] and responsibilities to family and community act as additional barriers to Indigenous people's engagement with the health system[8,9] and ultimately their decision to uptake and comply with cancer treatment. At the system level, it has been widely recognised that there is a lack of culturally appropriate tertiary health care services to engage Indigenous Australians[9,11-13]. Specifically, differences in communication and information needs, language barriers and challenges to continuity of care act as barriers to Indigenous people's engagement in cancer care[8,9]. Similarly, health professionals' views of and provision of care to Indigenous patients can enable or inhibit the provision of inclusive and culturally appropriate care[14,15]. Moreover, institutional racism — "ways in which racist beliefs or values have been built into the operations of social institutions in such a way as to discriminate against, control and oppress various minority groups"[16] — can manifest itself as intentional or unintentional discrimination or exclusion from the health care system[17]. Such institutional racism in the Australian health care system could further compound access to appropriate health care for Indigenous people with cancer[7,10,17-20].

Little is known about the experiences and perspectives of health professionals providing cancer care to Indigenous people. To improve cancer outcomes for Indigenous Australians and provide cancer care that better meets the needs of patients from diverse cultural backgrounds it is also important to understand assumptions and beliefs around Indigenous cancer care from the perspective of health professionals.

This paper reports on interviews conducted with health professionals within a broader study investigating the patterns of care of Indigenous Queenslanders with a cancer diagnosis. The aim of these interviews was to elicit health professionals' perspectives regarding Indigenous people's cancer experience and the factors that may influence health professionals' clinical decisions, particularly in the context of their patients' co-morbidities, Indigeneity, and access and use of cancer services.

Methods

This paper reports on data collected using semi-structured in-depth interviews conducted with a diverse range of health professionals. This approach was appropriate and in line with the study's aim to gain a deep understanding of health professionals' perspectives and experiences regarding Indigenous cancer patients[21].

Recruitment and sampling

Male and female health professionals providing a range of clinical and allied health cancer care services were recruited from a large tertiary hospital in Queensland, Australia. Purposive sampling was used to obtain information-rich cases relevant to address the research aim. Initially, the medical director of cancer services emailed health professionals who provide cancer care at the study site to introduce the study. Following this, an email containing a study outline and invitation to participate in a one-on-one interview was sent to the health professionals by members of the research team. Health professionals expressed interest in participating in the study by emailing the study research assistant (JM).

Data collection

Semi-structured in-depth interviews of approximately 30–45 minutes' duration were conducted by an experienced research assistant (JM) between March and July 2013 at a time and location convenient to the participant. A study information sheet was reviewed by the participant and written consent was obtained prior to commencement of the interview. The interviews were guided by a number of open-ended questions within a semi-structured interview guide. Participants were encouraged to answer in their own terms and reflect on their personal perspectives and/or professional experiences providing cancer care services to Indigenous Australians with cancer. All interviews were audio-recorded with the consent of participants.

Ethics approval for this study was obtained through the Human Research Ethics Committees, Menzies School of Health Research (HREC-2012-1758); Queensland Health, (HREC/12/QTDD/6); and the Metro South Hospital and Health Service (SSA/12/QPAH/334).

Data analysis

Interviews were transcribed verbatim, checked for accuracy and assigned a fieldwork number to ensure participants were de-identified. An inductive thematic analysis approach was undertaken to interpret the data. This approach organises the qualitative data by focusing on exposing patterns in experiences, expression, living, and/or behaviour expressed in the data[22]. To ensure codes and categories were grounded in the data, a comprehensive list of quotes relating to codes and categories was developed. Following this, possible relationships between categories were identified and discussed within the team to explain how they might relate to each other[22,23]. During the analysis process, concept maps were used extensively to form ideas and connections between ideas and to assist in consolidating concepts[24].

Reliability/validity

Reliability of the analysis process was enhanced by researcher triangulation. Independent analysis of transcripts was conducted by three researchers (JM, GG, HW) and ongoing discussions between members of the team (JM, GG, JA) reached consensus on codes and categories developed throughout the analysis process[25]. To satisfy internal validity of the findings initial codes and categories were systematically compared and contrasted with new observations in the data to ensure all codes were accounted for.

A reflexive approach was used throughout the project by memo writing following each interview to reflect on the interview, examine the influence of the researcher–participant interaction and its effect on the research process[23]. In addition, memo writing throughout the data analysis process was a mechanism to allow documentation of the decision trail of ideas about the data.

Findings

Twenty non-Indigenous health professionals, 14 female and 6 male, participated in this study. All participants worked in cancer care; registered nurses (n=4), allied health workers (n=5), medical oncologists (n=6), and radiation oncologists (n=5). Most participants (n=12) were aged 45–64 years and fewer (n=8) were aged 25–44 years.

While a small number of participants reported experience working in Indigenous communities at some time in their career, 50% of participants expressed little contact with Indigenous patients, and 50% reported personally knowing an Indigenous Australian as a patient or client. When asked if Indigenous patients in Australia could face the potential obstacle of discrimination, most participants agreed.

From our analysis, a number of categories were developed to explain a range of participants' perspectives and experiences relating to the provision of oncology care to Indigenous patients. The overarching concept of "difference" framed three main categories: "Acknowledging difference", "Not knowing how to accommodate difference" and "Not seeing difference" and a number of sub-categories developed from the data.

Acknowledging difference

Many participants acknowledged and described differences between Indigenous and non-Indigenous cancer patients. This was in terms of how health professionals perceived Indigenous patients as 'fitting into' health services, differences in Indigenous people's understanding of health and illness, experiences and expectations of treatment, level of support, socio-economic status and area of residence.

"Not fitting in"

Participants viewed the cancer treatment process for Indigenous cancer patients as more fragmented and protracted due to missed appointments, the patients' lack of understanding about how the health system works and an unwillingness or inability to engage in the health system amongst Indigenous patients. As one participant stated, *"I've got examples in my mind of ones that were sort of shocking and turn up once in a blue moon when somebody dragged them back and they very much saw it as a virtually antagonistic view I guess, towards the bureaucracy of the health system"* (participant 13). Many participants expressed how Indigenous people had a responsibility to accept or adapt to the biomedical system rather than the health system adapting and accommodating needs of a heterogeneous population. A participant noted, *"You've got to, honestly, you've got to fit in your environment. There is a responsibility and people need to be supported through that"* (participant 10). Further, participants reported challenges to appointment attendance could be explained by factors external to the health system such as the level of geographical remoteness, social circumstances and a lack of support. These factors were viewed as considerable barriers to the ability of Indigenous patients to engage in a range of health services, often resulting in treatment being modified.

Conversely, several health professionals acknowledged the system itself was inappropriate and not meeting the needs of Indigenous people, therefore a significant barrier to Indigenous people's participation in the health system for example, *"I mean they understand the complexities and just the sheer environment … they just don't come if they don't like it"* (participant 11, 12). The broader health system was described as presenting subtle discriminations towards Indigenous people through being rigid, complex, unfamiliar, culturally exclusionary and promoting a predominantly biomedical perspective.

Indigenous view of health and wellbeing: "A different vocabulary"

Several health professionals acknowledged Indigenous people's different perspective of health, cancer treatment and health services. For example a participant said, *"I've met some people who have always been holistic in treatment and never have done the Western medical setting and they really struggle with it, it's a real internal battle to keep going and then they get so sick and they're like … 'this is filling my body with poison, what am I doing?'"* (participant 17). In addition, participants spoke about how the connection of Indigenous patients' to family and land at times inhibited attendance and completion of their treatment. The interdependent nature of many Indigenous communities was discussed and compared with non-Indigenous communities. For example, a participant said, *"He wouldn't make a decision until he'd flown back to homeland and sat under the tree with the Elders and decided whether this was something he was going to do"* (participant 8). In relation to cancer treatment, many participants felt Indigenous people prioritised returning to home and family rather than undertaking hospital-based cancer treatment to prolong life, although cancer treatment protocols were acknowledged as being lengthy and following relatively rigid schedules. A participant stated, *"Often the priorities become about returning home and being in the community whereas I think with non-Indigenous people it's often about prolonging life and getting all the treatment in"* (participant 9).

"Personal experiences with racism"

Some health professionals reported they believed Indigenous people's views and interactions with the current health system stemmed from their past negative experiences from predominantly Caucasian staff and biomedical treatment within the health system. For example, *"I would think that the Aboriginal people, the Indigenous people would, given their experiences personal experiences with racism, then they probably would be very guarded when they came in here"* (participant 11, 12) and *"For the Aboriginal people coming from the communities that have had bad experiences with institutions … we all work for the same white person you know … don't trust you because they have seen all this awful stuff happen"* (participant 1).

In addition, health professionals recounted hearing a number of persistent assumptions about Indigenous people from other health professionals that contributed to them being viewed differently to other patients. For example, a participant explained, *"Certainly I hear people making I suppose value judgements about the Indigenous population"* (participant 7).

Not knowing how to accommodate difference

Some health professionals commented that their years of practical field and clinical experience had shaped the nature of their interactions with Indigenous patients. However, others reported their educational training and participation in

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cultural awareness courses did not equip them with a sufficient understanding of how to address the needs of Indigenous patients.

Communicating with Indigenous patients was described by participants as a challenge and they expressed doubts about their ability to adequately convey important information to Indigenous patients and indeed if the information provided was well understood by Indigenous patients.

Some participants also reported they were unsure about how to identify Indigenous people if Indigenous status was not recorded on their patients' medical file. In not knowing how to consider difference amongst patients, many participants described how they relied on their own values and beliefs to inform their interactions with Indigenous patients.

"They interact with you in a different way"

Participants described communication with Indigenous cancer patients as being different to other patients. Some referred to the provision of information about cancer diagnosis, treatment and outcomes as "giving the facts" which was mostly employed using what they believed to be simple English language.

Uncertainty: Participants described feeling unsure about the effectiveness of their interactions with Indigenous patients and raised concerns about Indigenous patients' capacity to understand information related to their cancer diagnosis and treatment. One participant commented, "*I thought I'd done a pretty good job with this fellow, clearly I've done a crap job because he hasn't been able to explain to his son anything*" (participant 20). A number of reasons for this uncertainty were suggested by health professionals; for example, Indigenous patients having lower literacy levels than non-Indigenous patients, being unfamiliar with the system and having different ways of communicating.

Participants reflected on experiences of their own and other health professionals' capacity to communicate effectively and engage in culturally appropriate conversations. In their experience, some participants acknowledged that, generally, health professionals were not always confident in their interactions with Indigenous patients. Participant 9 illustrated this when they said, "*I think some people would find it uncomfortable or maybe they don't know how to be around Indigenous people, they haven't had a lot of experience.*"

Disengaged: The health professionals suggested Indigenous patients were generally passive participants in the health system who often failed to engage in reciprocal communication regarding their cancer diagnosis, treatment and prognosis. It was suggested by some that, unlike non-Indigenous patients, Indigenous patients would not question or actively seek out information or treatment or follow up on test results, waiting times or postponed appointments. These circumstances were perceived by the health professionals as Indigenous people not advocating for themselves within the health system and potentially resulting in them becoming "lost in" or "left out of" the health system. Comments such as "*I would say a lot of them are quite passive and accepting … I would not be able to remember anyone Indigenous who … challenged me on why they had to have a treatment*" (participant 20); and "*They're not so independent in their thought than some of the others as you might expect … just not fighting their way into the system to start with*" (participant 15) exemplify this.

This perceived lack of engagement left many health professionals questioning Indigenous patients' levels of understanding and often resulted in them feeling unable to gain sufficient insight into the concerns and challenges Indigenous patients face relating to treatment or support. This was illustrated by a participant when they said, "*The Aboriginal patients seem to be a bit harder to identify what their concerns are, because they tend to shut down and sort of, I've just got to get out of here, rather than actually talking through it and being able to negotiate around things*" (participant 13).

"I cover it from my values and beliefs"

Participants reported they felt unable to presume an Indigenous patient's understanding of health and illness and therefore employed a biomedical approach to care. One participant stated, "*I can't presume to think what an Indigenous person would think. Again, I covered it from my values and beliefs so …*" (participant 11, 12).

At times, though there appeared to be disjuncture between care provision within a biomedical system and incorporation of Indigenous people's values within treatment decisions. While some participants acknowledged different beliefs, understanding and values between Indigenous and non-Indigenous people and emphasised patients informed decision-making, many still stated Indigenous patients' compliance with standard treatment protocol was "the right" decision to make. One participant underplayed the importance of language in decision-making when they said, "*I'm gonna tell you, I'll make you understand it, so I'll ask them to repeat what I've said … and then I say, now I respect whatever decision you take and most people do the right thing*" (participant 15). Meanwhile, providing patients with scientific facts about cancer diagnosis and treatment was emphasised; for example, "*I don't think I personally modify what I'm saying much based on which culture they come from. I guess most of our discussions are to do with just, scientifically based treatments rather than too much about what's happening to them … from us they largely just get the facts*" (participant 13). Several participants perceived this as freeing them from further responsibility for clarifying or communicating information to Indigenous patients.

Some participants' accounts alluded to Western values being imposed on Indigenous patients that led, in some cases, to alterations in their interactions with patients and treatment. Participants commented, *"I haven't seen any sort of obvious show of discrimination but I suppose it's like us isn't it? We see and eyeball even a white patient and we sort of weigh up things and see whether this person is able and then you sort of modify things"* (participant 21); and *"I've noticed Indigenous populations often tolerate treatment better. Because often alcohol masks a lot of symptoms development by cancer, particularly nausea and vomiting … but you have to give them higher doses too because they are often more resistant so it works both ways"* (participant 3); and *"It's really frustrating because there's so many patients that fall through the service because nobody's willing to pick them up. They're put in the too hard basket"* (participant 1).

Health professionals perceived Indigenous patients as having complex and challenging needs compared to many non-Indigenous patients and acknowledged Indigenous patients experienced subtle exclusion from the health system due to the system not accommodating different knowledge systems or expectations or due to a lack of enthusiasm by staff to incorporate different needs. As these participants stated: *"Just a sort of exclusionary atmosphere in a way I guess … there can be subtle discrimination really just in the health system"*; *"Particularly if you felt like you weren't sort of in a place where there was a lot of cultural understanding"* (participant 9); *"My experience of them is they don't feel comfortable in the health system"* (participant 7); *"A big concern is the fit you know, it's the fit you know helping people sort of fit"* (participant 10); and *"I think they see traditional Western medicine as a bit threatening"* (participant 4)

Indigeneity: "more westernised Aboriginal than Aboriginal Aboriginal"

There appeared to be concern amongst some participants about not knowing or assuming Aboriginal and/or Torres Strait Islander identity if it was not recorded or noted in medical records and some openly reflected upon whether this might influence or change their interactions and treatment. For example, a participant said, *"So I don't know whether it would have been of benefit to me knowing that he was Indigenous, whether I would have done things any better or any differently or what he would have wanted"* (participant 16)

Some participants acknowledged the effect of colonisation and noted there was not a distinctive homogenous Indigenous person with a definitive set of needs, which led many to fall back on treating everyone the same. One participant said, *"It's hard because there's no such thing as an Aboriginal person if you like, there's a very big spectrum as well, and so there's not any particular way that I've noticed that they approach things differently"* (participant 13). However, in some cases, assumptions were made by participants about Indigenous people that could be seen as misinformed, generalised or intolerant. Inappropriate racial definitions were used at times to classify Indigenous people and presented challenges for health professionals in providing culturally appropriate care. For example: *"Most of the Aboriginals we see are sort of more westernised Aboriginals than Aboriginal Aboriginal"* (participant 13); *"I can't even remember having treated a full blood Aboriginal for any real cancers"* (participant 21); *"One-sixteenth and they still call themselves Aboriginal and claim all the benefits that go with that, so you know fair people sometimes take you by surprise by saying, oh, I'm Aboriginal"* (participant 11,12); and *"With the truly rural Indigenous person I do think they have more cultural issues"* (participant 22).

Not seeing difference

Participants described treating all patients equally and some described the cancer experience for Indigenous people as not dissimilar to non-Indigenous people. Some participants diminished the importance of Indigenous identity and emphasised education and socio-economic status as more salient determinants to health.

"Treating everyone equal"

Participants commonly reported and highly valued a standard approach to cancer care for all to ensure a high standard of care, regardless of patient background. As one participant said, *You treat everybody the same and that but you're aware that you have you know their cultural differences"* (participant 10). In contrast, other participants highlighted the importance of not treating everyone the same by saying, *"Just got to do it person by person you know; you can't really do anything else because even if you've got two people from the same culture doesn't mean that they think the same"* (participants 18, 19); and *"Personally I treat everybody equal and give them the input that they need based on their needs"* (participant 2).

Although most acknowledged that patients are not homogenous and have different needs, some participants suggested the responsibility to adapt to the health system lay with Indigenous patients who should accommodate the dominant values about cancer diagnosis, treatment and prognosis into their belief system. A participant said, *"It's a one-size-fits-all, I mean in the end we've got to accept that belief system. The treatment that we're offering is for a condition that's largely the same no matter which culture they come from"* (participant 13).

"Not different depending on your Indigenous status"

Many participants talked about the importance of education and socio-economic status as critical factors influencing Indigenous patients' communication, engagement with the health system and their overall cancer outcomes. Indigenous identity was seen by several participants as distinct and unrelated to socio-economic status and/or level of education. Therefore socio-economic status and level of education were deemed to be more salient determinants of health than Indigenous identity alone. A participant offered a vivid example when they said, "*An urban Indigenous person who has grown up in Brisbane is just as, for the most part, comes across very similar to a non-Indigenous person. You know they have the same money issue, the same issues with parking, they have the same worries about their cancer, they have the same worries about chemotherapy. I think that's more of a socio-economic factor rather than an Indigenous factor*" (participant 22).

Their choice and responsibility

The concepts of choice and individual responsibility were strongly emphasised by a small number of participants. Health professionals used their own understanding of individualism as a platform to inform beliefs about Indigenous people's level of choice and individual responsibility in relation to cancer care and broader life decisions. Some participants implied choice was equally available for everyone and could override connections Indigenous people might have to people, place and culture. When describing compromises in health status as a consequence of where you 'choose' to live, a participant 22 said, "*That is obviously a trade-off you make, when you choose to live where you live … I think you've made a choice to live there, cannot expect the same amount of healthcare that you get in metropolitan Brisbane*". These choices or decisions were seen as a result of not being empowered, being victims of their environment or placing higher value on connection to family and land than their own wellbeing which acted as causes for cancer treatment disruption or neglect. The following comments illustrate this: "*I don't think they see themselves as empowered because you've brought up a generation who live off handouts*" (participant 8); "*At the end of the day they're an adult and able to make their own decisions. So if it's explained to them in a language that's acceptable: have a support worker and their family, and they sort of signed that they want to go home to somewhere really far away rather than prolong their life, that's no different to a non-Indigenous person making the same decision with the same facts*" (participant 22).

Discussion

This paper presents health professionals' perspectives and experiences relating to the provision of tertiary oncology care for Indigenous patients. Overall, the findings indicate some health professionals acknowledge and aim to address different needs and expectations of Indigenous cancer patients. However, it is also clear that some outdated assumptions and health system constraints limit their ability to address the needs of Indigenous cancer patients. In framing the health professionals' language within the scope of this study, it is not possible to distinguish whether the data reflects individual beliefs and views or whether it is highly influenced by health system constraints and the dominant discourse of broader society. Nevertheless, despite personal beliefs, health professionals in the tertiary setting work within the confines of a biomedical system which emphasises outcomes, outputs, individualism and curative, evidence-based medicine for healing[15,26]. However, this approach does not always acknowledge cultural diversity or the needs of different groups who engage the health system.

It is well known that barriers to health service access exist for Indigenous people and some services are not culturally appropriate and acceptable[27,28]. In this study, not all health professionals were confident in providing culturally safe health care despite most, if not all, previously completing cultural awareness courses. Some participants relied on their own values and beliefs to inform interactions with Indigenous people when unsure about how to provide a culturally safe service. In an attempt to train a culturally responsive medical workforce and to increase the number of Indigenous doctors, medical schools have included Indigenous health teaching into the curriculum[29]. Further research is required to determine the impact Indigenous health training has had on the values and beliefs of the medical workforce, as well as their ability to provide culturally competent health care in a range of hospital and health care settings. One regional health service in New South Wales, Australia, implemented a systematic organisational strategy to address individual and organisational racism in an attempt to improve the provision of culturally appropriate and accessible health care for Indigenous people[30]. They implemented multiple strategies, with the main focus being on staff education and training; supportive leadership from Indigenous and non-Indigenous members; and consultation, negotiation and partnerships with Indigenous community organisations to enhance Indigenous engagement and improve trust and respect[30]. While important change has been made, it has been recognised that it is complex and will be an ongoing process that will continue to require commitment from all staff.

Health professionals in this study were not always aware of a patient's Indigenous status due to status not being recorded on medical records and in patient files and they felt it was inappropriate for them to ask patients. Whether Indigenous status was known or unknown, many participants described treating everyone equal or with the same gold standard of treatment. Similar perspectives among health care professionals who addressed the complexities of difference by providing equal treatment to all have been previously reported[15,31]. Based on our findings, it is critical for health professionals to know and take into account Indigenous status to enable the provision of culturally responsive and acceptable cancer care.

Some health professionals in this study believed that socio-economic status and education were more important factors influencing a patient's cancer care experience more so than their Indigenous status. Further, while some participants reported treating everyone equally, others reported addressing individual needs of patients. Disregarding or downplaying race or culture and treating all patients equally, either consciously

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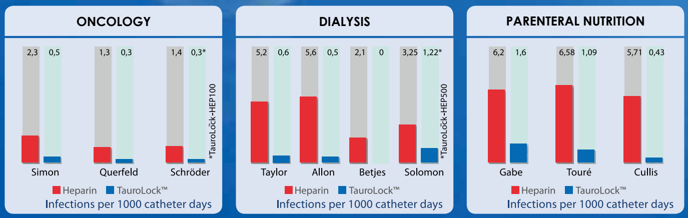

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* Punt, C.D., Boer, W.E. Cardiac arrest following injection of concentrated trisodium citrate, Clinical Nephrology, 2008, 69: 117-118. ** Willicombe, M.K., Vernon, K., Davenport, A. Embolic Complications From Central Venous Hemodialysis Catheters; Used With Hypertonic Citrate Locking Solutions, American Journal of Kidney Diseases, 2010, 55: pp 348 - 351. *** Polaschegg, H.-D., Sodemann, K. Risks related to catheter locking solutions containing concentrated citrate, Nephrol. Dial. Transplant. 2003, 18: 2688-2690. **** Schilcher, G. Polaschegg H.D. et al. Hypertonic Trisodium Citrate Induces Protein Precipitation in Hemodialysis Catheters, Selected ASN Meeting Abstracts, 2011

or subconsciously, may not provide the setting for culturally appropriate care[32]. The lack of culturally appropriate care can have significant implications for the uptake of services and treatment of Indigenous people[15,28,31,32].

Conclusion

The findings in this study highlight the importance of cultural competence training for all health professionals to improve the provision of culturally appropriate cancer care for Indigenous cancer patients. Cultural competence training should be embedded within all health training and workplaces and be part of ongoing systematic organisational processes in order to contribute to improvements in the provision of culturally appropriate cancer care and to encourage the uptake of and adherence to cancer treatment by Indigenous people. Consistent and accurate recording of Indigenous status in medical records is important to enable health professionals to identify Indigenous status in a sensitive and timely manner and to provide appropriate and relevant cancer care.

The study presented here highlights that discourse within health policy and services needs to adopt inclusive language and practice to acknowledge and provide for all who access the health system. This will go some way to addressing individual and institutional discrimination and racism as well as contribute to the provision of culturally appropriate health services.

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Conflict of interest declaration

The authors have declared that no conflict of interest exists.

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Improving the patient journey through better mental health care: core business for all nurses

Kim Ryan • Adjunct Associate Professor
CEO, Australian College of Mental Health Nurses, 9–11 Napier Close, Deakin, ACT 2600

Peta Marks • RN, BN, MPH, MCFT, Credentialled MHN
Professional Development Manager, Australian College of Mental Health Nurses, 9–11 Napier Close, Deakin, ACT 2600

Clare Butterfield • BSc, MComn
Communications and Publications Officer, Australian College of Mental Health Nurses, 9–11 Napier Close, Deakin, ACT 2600

Abstract

The evidence is clear that the mental and physical health of people is closely linked and has a reciprocal relationship. People with cancer are likely to experience psychological distress at various times throughout their illness, and a significant proportion will develop a mental health problem. There are many contributors to psychiatric morbidity in people who have cancer, including physical and biological issues, as well as psychological and social issues[1].

Displaying empathy and kindness, being genuine and understanding the psychological and emotional distress of someone who is experiencing a health crisis is the role of every nurse. During undergraduate education, all nurses should be developing knowledge and capacity around the interplay and impact on physical health by mental health issues and vice versa.

This paper discusses the importance of all nurses embracing, as a core part of their role, the ability to be able to understand and address the co-morbid physical and mental health conditions associated with complex health problems and chronic disease, and in particular cancer and mental health.

There is a well-documented but complex interrelationship between chronic diseases, such as cancer, and mental health[1], which can present challenges for nurses in terms of recognition and management. Mental health problems can impact on a person's capacity to optimally self-manage their chronic disease, increasing the burden of symptoms of the disease, and creating additional functional impairment[2]. Timely, accurate diagnosis and treatment of mental disorders is important, particularly in terms of improving the person's quality of life, and reducing the adverse effects of the mental health issue on the course of the chronic illness, the length of time spent in hospital, adherence to and efficacy of treatment, as well as prognosis and survival[1].

For some people, the experience of 'surviving' cancer can have positive outcomes — such as a greater appreciation and enhanced sense of purpose or meaning of life, or improved relationships with friends and family[3]. However, there is evidence of a significant association between cancer and increased rates of major depression and anxiety disorder, with around one-third of people with cancer who are hospitalised in an acute care setting being affected by a common mental disorder[1]. Even more significantly, approximately half of all patients with terminal or advanced cancer suffer poor mental health[4] and this has health impacts that affect not only their mental health, but their physical health — physical health outcomes are better when a person's mental health needs are addressed and worse when they are not[5]. For example, research shows that people with cancer who are also depressed and/or anxious experience a poorer quality of life, are often less adherent to treatment, are at an increased risk of morbidity and mortality, and can have a diminished will to live[6].

The practice of nursing is often described as 'holistic', meaning the mind, body and spirit are addressed[7]. For nurses to practise in a truly holistic manner they need to consider not only the physical, emotional, economic, social and spiritual needs of a person (who is also a patient), they also need to consider his or her response to illness and the effect of the illness on the individual's ability to meet their self-care needs. However, while nurses often describe their work as holistic, there is often room for improvement. Health care is complex and a patient's movement throughout the system often impacts on our ability to address all aspects of a patient's needs.

The focus on specialisation in nursing (and across other health professions) is understandable and desirable — there is a great body of knowledge associated with nursing and in specialised areas of practice. However, if this results in the patient/client/consumer being compartmentalised in the way their care is viewed, and, as a result, how they are viewed as a person, then this is less than desirable — for nurses, for patients and for their families. The process of compartmentalising care has disenfranchised many nurses from their profession (particularly those who embrace the notion of 'holistic nursing') and fragmented the nurses' role to such an extent that the concept of holism may actually now seem incompatible with how nurses see themselves, their practice and the patients[8].

All nurses, regardless of their 'specialty', need to be more cognisant of the interplay between physical and mental health and the care needs of people. For example, it is well known that the *physical* health needs of people with mental illness are often neglected[9]. People with mental illness experience poorer physical health, and higher morbidity and mortality as a result of their poor physical health, than people in the general population. This is evidenced by the fact that they die much earlier than the rest of the population — around 15 years earlier for women and around 20 years earlier for men[10,11].

For some groups of people, for example those diagnosed with schizophrenia and cardiovascular disease, death rates are two to three times higher than in the general population[12]. This morbidity and mortality can be ascribed to high levels of general modifiable risk factors, such as smoking and the impact of the mental illness on the person's capacity to engage in self-care health practices. It can also be related to other factors, like homelessness, poverty or trauma. For the most part, however, morbidity and mortality is due to:

- inferior preventive care — for example, people with mental illness are 30% more likely to die from cancer than someone in the general population because of low levels of regular screening, higher rates of some types of cancer such as lung cancer, and higher case-fatality rates (because of later diagnosis)
- lack of access to adequate physical care
- poorly coordinated care
- structural discrimination — which is evident when people with co-occurring mental and physical illness are treated less thoroughly and less effectively within the health care system. For example, people with mental illness presenting to emergency departments have been found to be less likely to be admitted for treatment of diabetic complications than people without mental illness presenting with the same symptoms[13].

This type of health inequity is a violation of an individual's right to health[9,13].

In the same way that the *physical* health needs of people with *mental* health problems have been neglected by nursing and other health care providers, so too have the *mental* health needs of people with *physical* health problems[14]. Both of these clinical scenarios are obviously concerning, because there is ample evidence in the literature of the reciprocal relationship between physical and mental health[15,16]. Poor mental health is associated with greater risk of physical health problems, and poor physical health is associated with a greater risk of mental health problems[16]. The *combined* effect of physical disease and mental ill-health has been linked with occupational disability, increased functional disability, poor quality of life, increased length of stay, poorer treatment adherence, poorer prognosis and accelerated mortality[17].

The literature around cancer and mental health specifically shows that:

- A significant proportion of people with cancer, at different stages of the disease trajectory, develop mental disorders[1].
- There is an association between cancer and increased rates of major depression and anxiety disorder — in fact, one in three people with cancer in acute care settings are affected by a common mental disorder — most frequently, depression[4].
- Death rates are as much as 25% higher in cancer patients who are depressed and 39% higher in cancer patients who receive a diagnosis of depression[18]. Less than half of cancer patients receive treatment for depression.
- Cancer survivors have a higher suicide rate than the general population — about double the incidence of suicide[19]. This risk is higher in men than women, and more common in those aged 65+ (and rates highest in men 80+ years), and is most common in those with prostate, lung, pancreatic and head and neck cancers. The first year after diagnosis carries a higher risk for completed suicide[19].
- Recent studies have found that adults with cancer and cancer survivors are at risk of developing cancer-related anxiety, including post-traumatic stress disorder and depression[20]. This is a direct result of disease-related experiences and generally goes untreated, leaving them at risk of having long-term psychological problems.

To provide holistic care it is important all nurses operate under the presumption that the people they are caring for are experiencing some degree of mental distress, and conversely that people with a mental illness may be experiencing co-morbid physical illness.

Everything about cancer is stressful — the cancer diagnosis, the impact of which will also be influenced by the person's age and life-stage; the type of cancer and prognosis; the biological effects of the malignancy; the symptoms of the disease such as pain and fatigue; the effects of the disease and treatment on a person's independence, functioning and role in life; and the direct effects of treatment, for example body changes related to surgery, as well as medication side effects such as hair loss and cognitive changes. Grief and loss, fear of death and of treatment, anxiety, uncertainty about the future, sadness and some degree of depression are also normal responses to what is undoubtedly a life-changing experience.

It is not only the patient that nurses will work with; the patient's family and loved ones will also be experiencing varying degrees of distress. Being a caregiver is associated with considerable psychological vulnerability, sleep disorders, and risk of alterations in the cardiovascular system, such as blood pressure changes[21], essentially, every nurse encounters mental ill-health frequently, regardless of their nursing specialty. As such, the *Enhancing Patient Journey* eLearning modules of education were developed by the Australian College of Mental Health Nurses. The aim of these modules is to provide non-mental health nurses more knowledge and skill (and hence confidence) to deal with the mental health problems they encounter.

While the cancer experience is different for everyone, there are commonalities, and nurses are acutely aware when someone is not coping well, or when they need extra support. All nurses — whether they specialise in cancer, mental health or another clinical area — provide emotional support as part of their role, and attempt to understand their patients' experience while mobilising the individual's strengths and resources to support optimal self-management. Whether aware of it or not, many nurses discuss mental health issues with patients and cancer nurses are already providing mental health care to patients and their families.

Nurses see people struggling to cope with the diagnosis, or with a recurrence after a period of remission; we see families, partners and parents who are frightened and grieving; we see people in their darkest hour and we understand the enormity of the person's journey. Whether a person is in need of 'support' or has a mental health problem like depression or anxiety, the fundamental aspects of a nurse's approach should be the same. For nurses to provide truly holistic nursing care, they need to address the physical, psychological, emotional and spiritual issues with *every* patient at *every* opportunity[7].

While some transient sadness or mild anxiety could be expected as 'normal' throughout a person's journey with cancer, depression and significant anxiety are not 'normal' and should not be expected[22]. If a person's distress is such that it is interfering with their capacity to engage with life, or if it makes it difficult for the person to cope with the illness, then it is likely that it is impacting negatively on their functioning, their capacity for self-care, their treatment adherence and the efficacy of treatment. If left untreated, this will have a negative impact on their health outcome. Providing psychological assistance to cancer patients early can have a profound impact on their mental wellbeing[23].

We must ensure that every person with cancer gets the psychological assistance that they need. To do this, a nurse must assess, identify issues and intervene where possible, and refer on to other health professionals when required. Specialist mental health nursing skills are not required. To provide the best care we can for patients, all nurses need to be willing to ask questions, listen to the answers and respond compassionately, raising with every patient the potential for an impact on their mental health as a result of the illness they are experiencing as part of day-to-day practice. Acknowledging this potential is important — a good place to begin; letting people know that struggling emotionally, or feeling overwhelmed is okay. Remind patients that they are not expected to cope 100% of the time and ensure that all patients know that if the way they are feeling is impacting on them in a significant way, that they shouldn't have to just 'put up' with that, or that it is to be expected.

Many nurses balk at the thought of asking questions about mental health. They are worried they won't have time to respond, that they are opening up a can of worms, that they don't know how to respond or that they will make matters worse. However, asking someone how they are feeling, whether they are coping, whether they are feeling sad or depressed may offer that person an invaluable opportunity for them to talk. It may simply provide them with a sense of permission to talk about how they are feeling, and that in itself can often be a relief for the person. Asking the questions also acknowledges that the feelings are real and significant, and it says to the person that the significance of their feelings is understood. Most importantly, it provides an opportunity for mental health support to be engaged — thus ensuring that the person really is receiving holistic nursing care. Responding to the mental health needs of all patients does not require the nurse to 'fix' everything — simply to fulfil their scope of practice as a holistic practitioner, identify issues and make referrals as appropriate — this is where the nurse's role as care-coordinator comes into play.

Patients, no matter their diagnosis, want to be treated as individuals, and that all their complexities are embraced as part of the picture.

While there is a continuing trend for nurses to identify themselves through the area in which they practise, such as cancer or mental health, we all need to remember first and foremost we are nurses and nursing is what we do.

Messner[24] in 1993 identified, in particular, that patients want nurses who:

1. Listen. Really listen. The patient will tell the nurse what they need if they are given the opportunity.
2. Ask them what they think and how they are feeling, rather than assuming to know how they are feeling because the disease process is well known.
3. Do not dismiss their concerns. Hospital life may be routine to nurses, but it is not to the patients.

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4. Do not treat them like a disease, but rather treat them like a person.
5. Talk to the person, not at them. As health care becomes more specialised, it becomes fragmented and nurses get busy with the duties of the day.
6. Respect their privacy.
7. Do not keep them waiting.
8. Do not tell them what to do without discussing it with them and how to do it in a way that is meaningful to them.
9. Keep them informed.
10. Remember who the patient is and who they used to be. This is particularly relevant when communicating with older people. Getting to know something about the person is often the key to a meaningful connection — it doesn't take too much time, but it is very powerful.
11. Let the person know that the nurse cares. Medicine and illness — be it cancer, or mental health — can be dehumanising.

All nurses should be encouraged to reflect on the care they provide, take those few extra minutes to talk and ask your patients what they need. The system often puts many strains on us, but we can't allow that to affect the care we want to and can provide to our patients.

Postscript

The Australian College of Mental Health Nurses Inc. (ACMHN) undertook the *Enhancing the patient journey: training nurses to integrate physical and mental health care project* funded by the Commonwealth Department of Health and Ageing. This project was undertaken in collaboration with colleagues from a range of nursing organisations, including the Cancer Nurses Society of Australia, to develop free eLearning continuing professional development resources for non-mental health nurses focused on identification and management of mental health and chronic disease issues. The resources included a series of live webinars, as well as the eLearning resources themselves (all available at www.acmhn.org).

The ACMHN's *Enhancing the Patient Journey* Project is about promoting good mental health care, about being aware of mental health problems and about intervening early. Physical pain is not ignored by health practitioners, nor should emotional pain — as it can be as damaging to the person and increases the potential for a negative health outcome. The project is not about educating all nurses to be mental health nurses, but rather it is about allowing nurses to better understand the mental health and physical health implications for patients.

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Exploring the preferences, perceptions and satisfaction of people seeking cancer information and support: implications for the Cancer Council Helpline

Anna Boltong • APD, BAppSci, MSc, MA, Grad Cert Eductn, PhD
Head of Cancer Information and Support Services, Cancer Council Victoria, Melbourne, VIC 3004

Monica Byrnes • RN, BAppSci, MAppSci
Manager Cancer Support, Cancer Council SA, Eastwood, SA 5063

Sandy McKiernan • RN, BAppSci, MPH
Cancer Information & Support Services Director, Cancer Council WA, Shenton Park, WA 6008

Nicola Quin • BBusAdmin, MIntBus, EMPA
Head of Division, Strategy and Support, Cancer Council Victoria, Melbourne, VIC 3004

Kathy Chapman • APD, BSc, M Nutr & Diet
Director, Cancer Programs Division Cancer Council NSW, Woolloomooloo, NSW 2011

Abstract

Background

Helpline services have existed in Cancer Councils for more than 20 years as an information and support service and gateway to a myriad of practical, informational and emotional support programs for people affected by cancer.

Aims

To explore public awareness and perceptions of the Cancer Council Helpline, including barriers and facilitators to calling this telephone service and user satisfaction.

Methods

An exploratory, mixed-methods study design was employed. In the qualitative phase, six focus groups were conducted with Helpline callers (n=14) and non-callers (n=28). In the quantitative phase, a community attitudes online or telephone survey was completed by people with a cancer diagnosis (n=128) and people who had friends and family with a cancer diagnosis (n=300).

Results

Low awareness of the service, as well as a widely held perception of not wanting or needing help, were found to be barriers to calling the Helpline.

Discussion

This research informed key elements of an identity refresh strategy for the Helpline, including public awareness and promotion with consumers and health professionals; and a name change for the service, including removal of the word 'help'.

Keywords Cancer information and support; helpline; supportive care.

Background

Unmet psychosocial needs are frequently reported by people with a cancer diagnosis and are highest during cancer treatment[1]. A recent study found that over 90% of cancer patients report at least one unmet need[2]. Similarly, almost all caregivers of people with a cancer diagnosis experience unmet needs[3], with 50% continuing to experience unmet needs six months post patient diagnosis, and 30% two years post diagnosis[4]. Accessing cancer information and support delivered by telephone can help people better understand their situation, improve the way they feel about it, and improve both confidence and interaction with their treating team[5]. Within the health care system, cancer helplines have a role in providing convenient, confidential information and emotional support to people affected by cancer, their family and friends, often as an adjunct to information received from medical teams or within their social networks[6]. Common reasons for calling cancer helplines include assistance with interpreting and understanding medical information received; emotional support and reassurance; requests for written information; discussions regarding treatment options; and aspects of care in advanced stages of cancer[7,8]. Although the internet is used with increasing frequency to access health information, evidence suggests that cancer helplines may be utilised more over websites for advice regarding "sensitive topics"[9].

In Australia, Cancer Councils exist in every state and territory as part of a federated structure with Cancer Council Australia (www.cancer.org.au). Cancer Council Australia works with its members, the eight state and territory cancer organisations, to undertake and fund cancer research; prevent and control cancer; and provide information and support for people affected by cancer. Helplines are available in every state of Australia, and each state has its own suite of information and support programs and services with some national programs and some tailored to local needs.

Nationally, the Cancer Council Helpline is an important resource for cancer patients, their families and friends, health professionals and in fact anyone seeking cancer information or support. The Helpline is accessed by dialling 131120 from anywhere in Australia. The caller's geographical location at the time of call will determine to which state's Cancer Council the caller is connected. Staffed by specialist oncology nurses and other allied health personnel, the 131120 service is viewed as a core function of the state-based Cancer Councils to help overcome geographical and social barriers and ensure those needing information and support can access it. Donations to Cancer Councils enable the Helpline to operate across Australia. Despite increasing cancer incidence and survival rates in Australia, calls to Cancer Council's Helpline have been steadily declining from nearly 70,000 in 2010 to the current level of approximately 55,000 per annum[10]. Possible reasons for this decline in telephone calls are low awareness of the service within the growing target population; diversification of cancer information channels; and evolving information seeking preferences, particularly with the proliferation of web-based content. There is now increased use of digital and online forums to access information and support via the internet and from social media; as well as better supportive care, including for survivorship, at the point of treatment and beyond; and a proliferation of cancer support organisations and forums, which provide more options for consumers to access timely information and support.

Aims

Cancer Council Australia sought to explore modifiable factors contributing to reduced calls and opportunities for more effective promotion of the Helpline service. In 2012 and 2013, a market research company was commissioned to undertake both qualitative (Part A) and quantitative (Part B) research to explore the following:

- Information and support needs of people affected by cancer (Part A)
- Preferences for accessing cancer information and support (Part A)
- Awareness and perception of the Helpline (Part A)
- Reasons for calling the Helpline (Part B)
- Service user satisfaction (Part B)
- Barriers to calling the Helpline (Parts A & B)
- Opinions on alternative names for the Cancer Council Helpline (Parts A & B).

Methods

This market research adopted a mixed-methods approach to addressing the research aims. An exploratory, sequential design consisting of an initial qualitative phase and building to a quantitative phase was used. A mixed-methods approach was chosen for this research in order to develop the research approach and to triangulate both qualitative and quantitative data. The integration of both types of data is thought to provide a research product to inform the Cancer Council Helpline marketing strategy in a way unlikely to be achieved through only one type of methodological approach.

Part A: Qualitative research

Focus groups (n=6) were conducted in Sydney and Perth during September 2012 by an independent and experienced market research company, accredited with the Australian Market Research Society, to explore the information and support experiences and views of people diagnosed with cancer. A semi-structured question route was used to guide the focus group discussions. An abridged version of this framework is shown in Table 1.

Criteria for inclusion were: i) age 35–65 years old; ii) fluent in English language; and iii) diagnosed or treated for cancer within the previous four years. For people who had not previously called the Cancer Council Helpline, recruitment company databases of people agreeable to participation in qualitative market research were interrogated for matches to the inclusion criteria. Potential participants were approached via telephone by an independent recruitment company who provided an overview of the market research exercise and invited participation. For focus groups aimed at previous Helpline callers, Helpline staff made the first approach to appropriate callers who used the service during the recruitment period, using a recruitment script and inclusion criteria to guide conversations. Callers gave verbal consent for their name and phone number to be passed onto the market research team.

Table 1: Semi-structured interview guide for focus groups

Questioning sequence
Cancer and the diagnosis experience
How did you feel when you were first diagnosed with cancer?
Have your feelings about cancer changed since you were first diagnosed? In what ways? What prompted the change over time (support, information, treatment, outcomes, contact with organisations, charities, other reasons)?
Information and support needs at diagnosis
How much did you know about cancer before your diagnosis?
How important is information at diagnosis?
What would you consider is the difference between information and support? What sort of information/support is needed?
Sources of information and support
With so much cancer information available, how do you know what information to trust?
Where did you go for information? How useful was it?
What about specifically for support — where did you turn? What did you wish was available?
Attitudes and experiences with cancer support organisations
Can you name any of the organisations that exist to support people with cancer? How do you feel about these organisations?
Thinking specifically about Cancer Council, how would you describe what they do? Where does your understanding of this come from? What are they best known for? How do they differ from other charities or cancer organisations? What are their services?
[If previously contacted the Cancer Council] Why contacted? What methods did you use to interact with the Cancer Council (Helpline, face to face, hospital information centre?) How was this interaction for you?
[If not previously contacted the Cancer Council] Why was the Cancer Council not an organisation you thought to get in touch with? Have you heard of Cancer Council's 131120 Helpline? How would you describe this service?
Did any of your doctors or cancer nurses suggest you call Cancer Council's 131120 Helpline? If they did, did you call? Why or why not?
Do you consider the Cancer Council a credible organisation to offer a helpline to cancer patients?
Would you be more inclined to get in touch with Cancer Council if there were other contact options (e.g. online, smartphone app, chat forums)?
Exploring the Helpline 131120 name
When you hear the term 'Helpline', what is the first thing that comes to mind? Is the name a barrier to people calling? What would be a better name to describe the telephone service provided by the Cancer Council?
[Activity]: Eight alternative names provided. Discuss options as a group: How do you feel about each name; what does it make you think of; why would it be a good name for the service? Why would it be bad? What are the preferred names?

All focus groups were audio-recorded. Content analysis of the focus group data was performed by two market researchers. Key themes were identified and listed in response to the categories covered in the focus group question route and any subsequent categories that participants discussed. Focus group data (passages of conversation) were allocated to the captured themes. A final list of themes and assigned data were agreed by two market researchers who facilitated the focus groups. These were verified by the primary author on listening to audio-recordings of the focus group discussions.

Part B: Quantitative research

Potential recipients of a 24-item open and closed question survey (estimated completion time of 10 minutes) were identified using databases of people registered to be approached to participate in quantitative market research. Inclusion criteria were: i) age 35–75 years old; ii) fluent in English language; and iii) diagnosed or treated for cancer within the previous five years, OR a direct family member or close friend of a person diagnosed with cancer within the previous five years. Surveys were administered online or via telephone according to participant preference. Data were analysed using descriptive statistics and frequency counts. Ethics approval was granted for this study by Cancer Council Victoria Human Research Ethics Committee.

Results

Part A: Qualitative research

In total, 28 non-callers to the Helpline (n=14 male; n=14 female) participated in four focus groups. An additional 14 people who had previously called the Cancer Council Helpline (n=5 male; n=9 female) participated in two focus groups. Details of the focus groups and participant characteristics are presented in Table 2.

Table 2: Characteristics of focus group participants

Date focus group conducted	Focus group type	Location of group	Participant Demographics
August 2012	Helpline non-callers	Perth metro region	Male: n=5 Female: n=2 Age range (years) 50–65
August 2012	Helpline callers	Perth metro region	Male: n=3 Female: n=5 Age range (years) 45–65
August 2012	Helpline callers	Perth metro region	Male: n=2 Female: n=4 Age range (years) 40–60
August 2012	Helpline non-callers	Sydney metro	Male: n=3 Female: n=5 Age range (years) 35–49
August 2012	Helpline non-callers	Sydney metro	Male: n=2 Female: n=4 Age range (years) 50–65
August 2012	Helpline non-callers	Sydney metro	Male: n=4 Female: n=3 Age range (years) 40–60

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Information and support needs of people affected by cancer

Focus group participants described shock, worry and fear when first learning of their cancer diagnosis. They described the speed at which 'everything happens' including treatment decisions; the feeling of being caught in a foreign world (medical terms, hospital setting); and the additional pressure of dealing with the needs of family and friends. These factors often meant information could not be absorbed at that time. Participants could clearly distinguish between information ("*The answers to your questions*"; symptoms, side effects, statistics, prognosis, risks) and support ("*Someone to listen to you*"; "*helping you to do something with the information*"; counselling) and expressed a clear need for both information and support outside of their place of treatment.

Preferences for accessing cancer information and support

The internet was a clear 'go to' source of information, particularly for younger people. Participants would often use information found on the internet to generate discussion with their doctors, especially in the context of clarifying things they had read. Despite using the internet frequently, there was a sense of an over-abundance of information, as well as challenges in finding relevant material and trustworthy sites. These factors sometimes led participants to avoiding online cancer information. One participant commented: "*I stopped looking at the internet — I found it scary and made things worse for me*".

Differences in information and support seeking needs, behaviours and attitudes were expressed by callers and non-callers to the Helpline. People who had previously called the Helpline tended to have complex queries and wanted more help making decisions or were seeking a second opinion. Often they called because they found it difficult to access information in the form they wanted elsewhere. Some participants described factors such as disappointing interactions with their doctors or rushed consultations where explanations were felt to be limited, as contributors to their decision to call the Helpline. Others said that being prompted by a nurse, doctor or friend encouraged them to call.

Helpline non-callers displayed more stoic attitudes and appeared more self-reliant *("I just got on with it*") or did not want too much information. In the non-caller focus groups, the theme of more positive doctor–patient interactions was apparent. Additionally, non-callers were not prompted to call the Helpline by their doctor or nurse.

Awareness and perception of Cancer Council and its Helpline

Participants' impressions of Cancer Council focused mostly on the provision of information (easy-to-understand brochures and booklets, especially on types of cancer) and other aspects such as fundraising and research. There was less recognition of *support* for cancer patients or carers or the Helpline service itself. For example, when cancer patients were asked what Cancer Council was best known for, common responses regarded organisational priorities such as cancer prevention; research on specific cancer types; and specific campaigns including Daffodil Day and Slip Slop Slap. No participants mentioned the Helpline when unprompted.

Reasons for not using the service among Helpline non-callers were no prompting or encouragement ("*My doctor never told me about them, in fact nobody did*"); lack of awareness or understanding of the service ("*There's lots I don't know about them and what they have available*"); support available from elsewhere ("*I had enough support from the breast cancer nurses*"); or not needing help as such ("*I didn't need help so I didn't think I needed to contact them*"). There was a misconception among some non-callers that the Helpline was staffed by volunteers, students, retirees or survivors and some felt unclear about the level of training or qualification of the Helpline staff ("*Are they qualified?*"; *"Are they trained?*"). Non-callers thought that the service was aimed at those having more problems coping with their cancer than themselves ("*It's for people in real need of help*") and who were experiencing crisis situations ("*It's like a lifeline for people with cancer*").

Those who had called the Helpline described positive experiences with regards to information ("*They gave me the answers I was looking for*") and support ("*I found someone who would listen when I was down or when I just needed to talk to someone. They included my husband too which was important for him*"). The particular *way* in which information was delivered (unhurried, simple and easy to understand) was also highlighted by some participants ("*It's information in a supportive way*"; "*They gave me a lot of time and were never in a hurry*").

An element of surprise was apparent when callers realised the range of information and services accessible via the Helpline which then changed their perceptions and views of the service ("*Until I called them, I didn't realise they had so much practical support and assistance*").

Opinions on alternative names for the Helpline

Participants responded most positively to the proposed name "*Cancer Information and Support 131120*" for its clarity of communicating what the service does and its positivity and detraction from 'those in need'. Other options were rejected for their impression of counselling (CanSupport 131120) or sickness (Call a Cancer Nurse 131120) or because they were perceived as impersonal (Cancer Information and Resources 131120). Importantly, participants thought the preferred new service name would inspire people to call.

Part B: Quantitative research

Of 509 eligible participants, 428 completed a survey (84% response rate). Sample group characteristics are presented in Table 3.

Table 3: Characteristics of survey respondents

Demographics	**n (%)**
Sex	
Male	167 (39)
Female	261 (61)
Age (years)	
35–44	120 (28)
45–54	116 (27)
55–64	111 (26)
65–75	81 (19)
Location of residence	
Metropolitan area	270 (63)
Rural area	158 (37)

Of the entire sample, 30% (n=128) were people who had received a cancer diagnosis and 70% (n=300) were friends or family members of someone who had received a cancer diagnosis.

Reasons for and barriers to calling the Helpline

In the two-year period prior to completing the survey, only 3% (n=11) of respondents had called Cancer Council's Helpline. This was predominantly to clarify information already received, to seek more detail on a topic — including to request information regarding the evidence base or research findings to substantiate advice previously received. Those who were aware of the Helpline (n=128; 30%) were most likely to have first heard about the service from advertising or promotion rather than from a doctor or nurse (Figure 1). Of the entire sample (n=428), only 4% could recall having a clinician recommend they call the Helpline. More than half of respondents (n= 218; 51%) indicated they were more likely to call the Helpline if it was recommended to them by a clinician. Reasons provided for not having called are shown in Figure 2 and predominantly stem from a lack of perceived 'need'.

Service user awareness and satisfaction

The most common response to the question,"*What services would you say the Cancer Council Helpline provides to those with cancer and their family and friends?*", was "I don't know" (n=94; 22%). Only 4% of respondents (n=17) could name the Cancer Council Helpline phone number. Of those who had called the Helpline, most (n =10; 91%) were more than satisfied with the service with 73% (n=8) reporting they would be likely to call again.

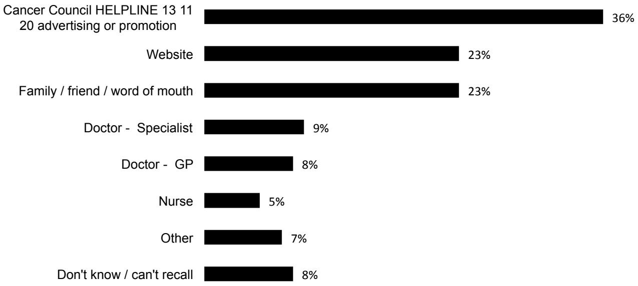

Figure 1: How those aware (30%) first heard about Cancer Council Helpline 131120

Figure 2: Reasons for not calling Cancer Council Helpline 131120

Opinions on alternative names for the Helpline

Of six possible names for the Helpline service put forward in the survey, the title "Cancer Information and Support 131120" was preferred by 43% of the sample (n= 90), with a mean liking rate of 7.7 where 1 = *Don't like at all* and 10 = *Really like*.

Discussion

Both qualitative and quantitative components of this research support the following key findings that underpinned a Helpline rebrand campaign for Cancer Councils in late 2014:

1. Awareness of the full range of Cancer Council information and support programs and services could be improved.
2. The credibility and professional staffing of the 131120 service should be reinforced.
3. The word 'help' supports misconceptions about the nature of the service.
4. Health professional endorsement of the 131120 service is likely to promote service engagement.

Provision of supportive cancer care via nurse-led cancer helplines

Addressing unmet psychosocial needs in people affected by cancer and their carers is important to promote optimum physical, emotional and social functioning[11]. Phone-based supportive care models are increasingly being framed and implemented as a cost-effective method of addressing informational, emotional and practical needs of people affected by cancer and their carers[12,13]. Although a recent systematic review of the effectiveness of cancer helplines[12] suggested that more intervention studies are required to determine effect on wellbeing, two randomised controlled trials have provided evidence of the psychosocial benefit of helplines. Livingston *et al.* (2006) showed that outcalls from Cancer Council's Helpline supported positive thinking, thinking through things and talking with doctors in a sample of 100 men diagnosed with colorectal or prostate cancer. Samarel demonstrated benefit of reduced mood disturbance and loneliness in 125 women with breast cancer[14].

Briefly, the rebrand strategy designed to increase service use included: i) a service name change to "Cancer Council 131120" with the accompanying descriptive line, "for information and support"; ii) developing a marketing strategy to increase community awareness of Cancer Council's telephone-based support and information service; and iii) a communications campaign to increase health professional engagement and referral to the service.

Improve awareness of the full range of Cancer Council information and support programs and services

As well as providing information, emotional support and referral options, Cancer Council Helplines are the conduit for a range of psychosocial programs and services, including peer support, which are shown to be effective in reducing psychological distress[15], as well as practical programs that may include financial support and counselling, known to be sought by both patients and their carers[3]. It is often not until a person makes contact with a service that they become fully aware of the range of supports available. This notion of 'you don't know what you don't know' was supported in the current study as participants learned about specific services that were available — these were identified as having been potentially useful earlier in their cancer journey had they have known of them. Knowing more about what is actually on offer gives people greater clarity about why to call the service. This is relevant to both consumers and health professionals, given the suggestion that clinician endorsement of cancer helplines encourages service uptake by people affected by cancer.

Reinforce the credibility and professionalism of the 131120 service

Success of phone-based supportive care models are contingent on the perceived credibility of the health professional moderating the service[6], including credentials and therapeutic communication competence[13]. A core component of the 2014 Helpline rebrand campaign was reinforcing, via conspicuous promotional material, that the information and support service is staffed by suitably qualified, specialist personnel. Prominent branding included the slogan *Cancer Council 131120: Patient support you can trust,* depicted an oncology nurse and was accompanied by testimonials provided by prominent supportive care oncology clinicians.

The word 'help' is unhelpful

The market research data support a change of name for the Helpline as it showed that the perception of not wanting or needing 'help' is a barrier, preventing calls being made to the service. A name change may increase the likelihood of calling the service.

Engagement with clinicians

Recent research suggests that receiving a health professional's recommendation for a service at a salient point in their care can increase uptake of these services; however, few clinicians regularly refer patients to cancer information and support services[16], with many also lacking awareness of what Cancer Council information and support programs and services can provide to patients[17]. The engagement of health professionals with the evidence-based nature and range of programs and services provided via the 131120 service, as well as the clinical credibility of those programs, is absolutely critical to the uptake of support services. Cancer Council continues to pursue strategies that engage medical, nursing and allied health professionals to recommend that their patients call 131120 at diagnosis, during or after treatment or when asking for information in general. Previous research has shown that only 4% of patients called an information service when simply handed a pamphlet[18] so more targeted referral mechanisms are needed.

Study limitations

In interpreting the findings of this study, self-selection bias needs to be considered as a potential limitation. Although study participation was voluntary and individuals were not targeted for inclusion, those that did participate might be classified as 'engaged' with their own health care or the care of someone close to them. Participation assumes a level of health literacy as well as a command of the English language. The inclusion of participants who were up to five years post diagnosis may not have captured the views of those with potentially highest unmet psychosocial needs at the time of immediate diagnosis in the cancer support context. Conversely, those with robust health and social support networks may have been less interested in participating in the study, or of using the Helpline. As suggested in a recent systematic review of the benefits of cancer helplines[12], certain population types, including people affected by more debilitating cancer types, may have more to gain from telephone-delivered cancer information and support and therefore have greater expressed improvements in psychosocial outcomes.

The time period between initial cancer diagnosis and participation in focus groups or surveys asking about initial reaction to diagnosis for some participants was up to five years. As such, recall bias may be a factor with regard to conditions surrounding diagnosis or follow-up treatment, including information-seeking behaviours, especially if informational needs and support experiences have changed over time. Questions about information seeking are still thought to be relevant, despite this time period. For context, information-seeking behaviours were still prominent in survivors for a mean of 10.5 years since cancer diagnosis in a study that examined differences between 'seekers' and 'non-seekers' of cancer information[19].

Future directions

The effectiveness of Cancer Council's Helpline identity refresh strategy will be evaluated using national and state-based datasets reporting changes in caller numbers and uptake of services.

Recommendations for further research

Repeated research regarding cancer information and support needs and preferences; awareness and perception of the Helpline, and reasons for calling the Helpline could in future utilise purposive sampling in order to garner views from people with specific clinical or demographic characteristics. Conducting similar research with people identifying as culturally and linguistically diverse (CALD) may provide useful insights into the specific information and support needs, and experiences, of CALD populations. Examining the use and perceptions of Cancer Council's interpreter service, which provides cancer information and support in languages other than English via qualified interpreters is recommended.

Little is known about the information and support needs of people who are informed about, but elect not to call, cancer helplines. Research that leads to clearer user profiles and stratified pathways of care and referral to community-based cancer information and support such as cancer helplines is advocated. Gathering data from people who elect not to call the 131120 service after being given information about it, may eliminate any halo effect that the current research design may have supported.

Ongoing evaluation of the impact of telephone-based cancer information and support services on patient outcomes should be undertaken in order to contribute to the evidence of effectiveness of such services beyond service use and customer satisfaction. Not only will better evidence support ongoing quality maintenance and enhancement, but, importantly, should drive greater numbers of people affected by cancer to this valuable service.

Practice recommendations

The current research reinforces that health professionals and consumers should have access to information on the full range of available cancer information and support programs and services. Cancer Councils should continue to work with clinicians to develop referral pathways tailored to specific patient information and support needs. Education and promotional activities will be targeted accordingly and evaluated. A process of tailored information and support on prescription is currently being trialled as a method of integrating routine referral to cancer information and support services in the clinical oncology environment. This work is being undertaken in a practice-research partnership between Cancer Councils and clinical oncology services in a range of clinical contexts at multiple stages of the cancer treatment trajectory, in both rural and metropolitan-based health services. The outcomes of this research should inform practice in the clinical setting.

Diversification of communication channels for cancer information and support, such as digital and social media channels, may increase service accessibility and be perceived to offer a further level of convenience and anonymity among some consumers. These communication channels should be promoted widely to both health professionals and consumer groups in order to optimise patient choice.

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Cancer Nurses Society of Australia

Management of toxicities related to intravenous administration of epidermal growth factor inhibitors

Marie Condon • RN, BSc Nursing, PG Cancer Nursing
Nurse Manager, Cancer Centre, St John of God Murdoch Hospital, Murdoch, WA

Gail Ross-Adjie • PhD, MClinN, CCU Cert, RN, MACN
Nurse Researcher, Centre for Nursing and Midwifery Research, St John of God Murdoch Hospital/University of Notre Dame Australia
Murdoch, WA

Leanne Monterosso • PhD, BNurs(Hons 1), RN, RM, NNT, FACN
Chair of Nursing (Clinical Research), Centre for Nursing and Midwifery Research, St John of God Murdoch Hospital/
University of Notre Dame Australia, Murdoch, WA

Abstract

The use of newer targeted cancer therapies, including tyrosine kinase inhibitors (TKI) and epidermal growth factor receptor inhibitors (EGFRI) in the solid tumour groups can often result in a complex suite of cutaneous side effects. Whilst not systemically as toxic as some traditional chemotherapy agents, their cutaneous side effect profiles may have a considerable impact on the patient and their health-related quality of life[1-4].

Currently in Australia, cetuximab and panitumumab are the only intravenous EGFRI agents subsidised on the Australian Pharmaceutical Benefits Scheme[5,6]. This discussion paper focuses on the nursing management and patient education related to the administration, side effects and adverse events associated with these two EGFRIs. While the side effects of panitumumab closely resemble those experienced by patients receiving cetuximab, the literature is often not specific about which agent when discussing adverse effects and management[3,5-8]. However, where there is variance between the incidence or management of the adverse effect it will be highlighted.

Background and literature review

Epidermal growth factor receptor inhibitors (EGFRI) including monoclonal antibodies and tyrosine kinase inhibitors[4] are providing new and targeted therapies for patients with solid tumours and are associated with improved response and survival outcomes when they are used as single agents or in combination with chemotherapy[1-3]. These agents are used in different tumour groups including, though not limited to, colorectal, head and neck, lung, breast, renal cell and pancreatic cancers[9-12]. Whilst the side effect profile of these new agents is not systemically as complex as standard chemotherapy, there are a suite of significant cutaneous side effects with which the oncology nurse should be familiar[3,10,13-15]. For the purpose of this discussion paper, only colorectal cancers will be discussed as they are the only tumours being treated by intravenous administration of EGFRIs outside possible clinical trial settings.

The visual nature of the cutaneous side effects following EGFRI administration may decrease the patient's ability to keep their disease and treatment private, resulting in social isolation, challenges to body image and potential difficulty with intimacy and relationships[12,16].

Oncology nurses are well positioned within the health care team to recognise these unique side effects, tailor patient education and management strategies to best minimise the impact of the toxicities on their quality of life and enable them to adhere to their treatment plan[17-19].

A review of the literature was undertaken using the CINAHL, Medline and PubMed databases. The search was limited to English, the years 2007–2014 and used the keywords: epidermal growth factor receptor inhibitors; EGFRI; skin toxicities; cutaneous toxicities; cetuximab; panitumumab; nursing management; patient education. Relevant articles have been used to inform this discussion paper as a resource for nurses who care for these patients.

Boers-Doets and colleagues[16] suggest that some patients may cease their treatment based on the look and discomfort of skin eruptions and their complications. It is imperative, therefore, to minimise the effect of these cutaneous lesions on the patient through early recognition, effective management, education and support by the oncology nurse as part of a comprehensive interdisciplinary approach to the care of the patient receiving EGFRIs[10,12,20]. Clinical studies in patients undergoing treatment for colorectal and squamous cell carcinoma of head and neck have demonstrated a correlation between the skin rash associated with EGFRI medications and efficacy of the drug[12,16,20] but the cutaneous side effects can contribute to a decline in health-related quality of life[3,8,12,13,20-22].

These specific toxicities can have considerable impact on the patients' wellbeing including their physical, emotional and social functional domains which are measured in quality of life surveys[13]. Pinto and colleagues[21] suggest that through the appropriate management of the cutaneous toxicities associated with the administration of the EGFRIs it is possible to ensure that adequate drug dosing occurs, improvement in quality of life is achieved and survival outcomes are positively impacted upon.

Epidermal growth factor receptors

When intracellular epidermal growth factor receptors (EGFRs) are activated they initiate downstream cellular pathways which regulate cell growth[9]. Skin, sebaceous and sweat glands, hair and nails as well as the endothelium present in the dermal capillaries are the normal body tissues in which EGFRs are found[15]. EGFRIs are over-expressed on many solid tumour cells and are closely associated with the development of cancer and increased metastatic spread with a poorer prognosis and a reduction in survival[10,21]. EGFRIs act in a targeted fashion against selected pathways, which are vital for the tumour to grow and survive, though for normal tissues that express EGFRs this signalling is crucial for normal functioning[3]. As a result of this disruption to the signalling pathway and cell functioning in normal body tissues expressing EGFRs, the toxicity profile is primarily cutaneous and includes an acneiform rash on the face, neck, trunk and upper back; changes in hair growth; xerosis and fissures and nail changes including paronychia[4,8,11]. These side effects can lead to reduced quality of life, dose modification, delay or cessation of treatment[8,16,20].

Monoclonal antibodies used to inhibit EGFR

Cetuximab (Erbitux®) is a chimeric immunoglobulin G1 monoclonal antibody[17] used in the treatment of metastatic colorectal cancer in combination with irinotecan-based therapy[6], and squamous cell carcinoma of the head and neck[8,9,11,22]. Panitumumab (Vectbix®) is another EGFRI agent that has been listed on the Australian Pharmaceutical Benefit Scheme[5] recently, for use in patients with metastatic colorectal cancer. This medication differs to cetuximab in that it is a fully human immunoglobulin G2 monoclonal antibody[23]. Panitumumab is administered either as a single agent or in combination with irinotecan-based therapy[23].

For the patient to be eligible to receive either of these EGFRI agents, their primary tumour must express Kirsten Rat Sarcoma (K-RAS) viral oncogene wild-type gene[24]; however, for those who have mutations of the K-RAS gene, neither of these medications are available for use nor are they recommended[24,25].

Administration guidelines

The administration of both cetuximab and panitumumab is via the intravenous route. It is recommended that cetuximab be administered weekly following premedication with an antihistamine and corticosteroid[24] given 30–60 minutes prior to the infusion[7,26]. There is no requirement for an inline filter and the rate of administration should not exceed 10 mg/min in either the loading dose or subsequent doses[24]. It is recommended there is a pause of 60 minutes between cetuximab and commencement of chemotherapy[7]. As panitumumab is a fully human monoclonal antibody there is no need for premedication[18]. It is administered fortnightly at a rate not exceeding 10 mg/minute via an infusion line inclusive of a 0.22 micron filter[23].

Hypersensitivity reaction management

Cetuximab is a monoclonal antibody which is a chimeric mouse-human molecule[7,26]. Patients receiving cetuximab infusions are at risk of hypersensitivity reaction with the reported incidence ranging between 3% and 10%. The severity of hypersensitivity reactions varies, although anaphylaxis may occur[7,17,26]. Hypersensitivity reactions are mediated via an antigen-antibody reaction where the immune system is stimulated by an antigen[27]. Exposure to the same antigen will engage these antibodies, leading to stimulation of the inflammatory mediators including histamine and serotonin, producing an anaphylactic response[27]. In their study of hypersensitivity reactions related to cetuximab across the United States, George and colleagues[26] describe an increased incidence of reactions in more rural centres. Whilst the aetiology of this is not completely understood, they suggest an increased pre-exposure to mouse populations and high levels of IgE create antibodies before treatment, with hypersensitivity reaction estimated at <1% in New York and up to 22% in North Carolina and Tennessee. Because of the distribution of populations through rural areas where there may be increased exposure to ticks and mice, there may be similar implication for treatment centres across Australia[28].

Anaphylactoid responses differ from anaphylactic reactions in that they do not require the patient to have any prior exposure to the agent before a reaction can take place[27]. Cytokine release syndrome is an acute infusion reaction, which is mild to moderate in its intensity during the infusion[10,16,22,29] and up to 24 hours after completion[27,30]. It manifests as nausea, headache, rash, tachycardia, hypotension and dyspnoea[30,31]. Both anaphylactic and anaphylactoid reactions require the same management strategy should they occur[17,27,31]. Nurses administering drugs which have the potential for hypersensitivity reaction should have a clear understanding of the signs and symptoms of an hypersensitivity reaction as well as their immediate management as they can be life-threatening[31]. Although panitumumab is a fully human monoclonal antibody and the risk of hypersensitivity reaction is markedly reduced, severe reactions have been reported in 0.5% of patients[23].

Electrolyte imbalance

Patients receiving these EGFRI agents should have their electrolytes closely monitored as there is the potential for an imbalance of magnesium, calcium and potassium concentrations progressively during treatment and up to eight weeks post cessation of treatment[7,23,32]. Magnesium is reabsorbed in the ascending loop of Henle, which has a high EGFR expression, thus the disturbance of this function may contribute to hypomagnesaemia[33].

Acneiform rash (also referred to as papulopustular rash)

The development of an acneiform rash is the most common side effect of both cetuximab and panitumumab, with the incidence reported up to 86% and 93% respectively[18,23,27,34-37]. The literature describes considerable variation in the onset of the rash, which may occur within days[4,12,15,20] or in the weeks after administration[10,16,22,29], with consensus that peak incidence occurs at four to six weeks and diminishes over time, often without treatment[8,15,20,21,29].

The acneiform rash is variously described in the literature as an eruption of papules and pustules, typically appearing on the face, scalp, upper chest and back[30]; a superficial suppurative folliculitis, which does not have an infectious source[11]; a rash characterised by monomorphous pustular lesions[9] and an acneiform rash similar to acne but itchy with an absence of white and black head comedones[15]. Tomkova and colleagues[11] concede there is little published work examining gender differences in the incidence of cetuximab-induced acneiform eruptions, although the authors did speculate whether there was some interference in blockade of EGFR pathway in relation to androgen metabolism and functioning. Lacouture and colleagues[10] report that men had a higher incidence of cetuximab-induced acneiform rash and that those over 70 years were at risk of a more severe rash. Approximately 15% of patients may experience a grade 4 rash, requiring an adjustment to the medication dosing and a delay in therapy[29].

Pathophysiology of acneiform rash

EGFRs play an integral role in the development and function of normal skin; therefore, when the EGFR pathway is blocked there are a significant and unique sequelae of cutaneous reactions[20]. EGFRs are expressed in the keratinocytes occurring in the hair follicles and also in sebaceous and sweat glands[15,16,20,38]. Inhibition of EGFR contributes to a disturbance in the balance between multiplication and differentiation of cells[15], leading to derangement of hair follicles in seborrhoeic areas of the patients skin (primarily the T-zone of the face, neck, scalp, shoulders, upper trunk and chest)[4,15,16,20].

Assessment and management

Accurate assessment of the rash is integral to assessing the response of the patient to the interventions put in place to treat the toxicity[8,39]. For consistency in reporting and management, the rash should be graded according to the 2009 Common Terminology Criteria for Adverse Events, version 4 (CTCAE)[12,30].

Whilst there is some variation in the recommended management of the acneiform rash, education is a recurring theme. Accurate and targeted education for both the patient and their significant others may mean there is less likelihood of a dose reduction related to toxicities, and maintenance of the patient's health-related quality of life and better adherence to the cancer treatment program[4,16,20,40,41]. Whilst there are few robust studies examining the management of these debilitating side effects, the need for a proactive and preventative, multidisciplinary approach is a consistent theme within the literature[2,10,13,17,21]. Current management is detailed in Table 1.

Xerosis and fissures

Xerosis is defined as "pathologic dryness of the skin"[42]. This dryness may exist concurrently with the acneiform rash or immediately following the reduction in the acneiform rash, and may continue for months[10,16]. It presents as itchy, dry and scaly skin where the acneiform rash had been, but also on the arms and legs[10,16,38]. The incidence of xerosis in patients who have received intravenous EGFRIs has been reported as between 35% and 100%[3,9,20,24,41] and results from a deterioration in the stratum corneum and a decrease in loricrin, the main protein which acts as the infrastructure of the epidermis[8]. The degeneration and damage to the epidermal layer results in tissue that cannot retain or preserve moisture and is more common in older patients, those who have pre-existing eczema and those who have had prior chemotherapy[8,16]. As a result of xerosis, fissures, which are deep furrows, clefts or slits[42] may occur on hands and feet, especially on the knuckles and dorsal folds of hands and fingers, under the nails and on the patient's heels[15,20]. Fissures may not become evident until up to two months of treatment with an EGFRI[8].

Table 1: Acneiform rash management

Management strategies	Rationale/evidence
Warm water when bathing	Decrease irritation and discomfort of hot water due to skin sensitivity[15,20,21,44]
Soap- and alcohol-free products	Prevents further drying and irritation of the damaged skin[15,20,40,43]
Emollient creams/ moisturisers	Early use of Vitamin K cream before rash avoids drying of the skin[4]; however, some studies did not recommend as no formal trials had endorsed this[40] ;others eluded to studies that are under way[44] Frequent application is recommended[15,17,19] One per cent hydrocortisone cream with moisturiser is recommended[10]
Avoidance of sun exposure	Use of non-occlusive sunscreen[21,34,44] SPF 30 or greater[4,10,17,19,41] Sun-protective clothing
Avoid greasy ointments on the face and trunk	Greasy ointments may prevent moisture loss, thereby increasing the risk of superinfection[19]
Early use of systemic tetracycline class antibiotic therapy	Minocycline 100 mg daily or Doxycycline 100 mg twice daily (minocycline has an anti-inflammatory property which has been found to be most useful[17,19,21,34,44])

Paronychia and periungual effects

Paronychia is a painful disorder characterised by a suppurative inflammation of the nail fold surrounding the nail plate[42]. The periungual effect refers to the area around the nail bed[42], which may present as a pyogenic granuloma-like lesion[8]. The patient receiving infusions of EGFRI may experience a combination of slowed growth of the nail and changes in the strength of the nail from the nail bed at the disto-lateral origin[43]. Paronychia leads to significant pain and reduced physical function affecting the ability to manage activities of daily living[10]. It occurs in approximately 10–30% receiving EGFRI therapy with the incidence greater in patients receiving panitumumab[44] and occurring primarily on the thumbs and great toes[3,8,15,20,38,43,44]. Paronychia leads to significant pain and reduced physical function, affecting the ability to manage activities of daily living[10]. Paronychia and periungual effects can occur up to eight weeks after commencement of intravenous EGFRI therapy[8,16,38,43] and whilst it is a sterile process[8], it is often complicated by *Staphylococcus aureus* infections or gram-negative bacillus[2,19,43,45] requiring antibiotic therapy[45] and analgesia[19,46].

Galimont-Collen and colleagues[15] suggest that although there is no firm data on the pathophysiology of paronychia in this patient cohort, it is possibly related to an increase in the penetration of nail fragments into the periungual tissue as a result of epidermal thinning induced by the EGFRI agents.

Table 2: Management of xerosis and fissures

Management strategies	Rationale/evidence
Xerosis	
Warm water when bathing	Decrease irritation and discomfort of hot water due to skin sensitivity[15,20,21]
Soap- and alcohol-free products	Prevents further drying of the skin and irritation of the damaged skin[15,19,21,34,44]
Use of emollients containing urea 5–10%, colloidal oatmeal, petroleum-based creams	Assists in rehydration If severe xerosis with inflammation may benefit from steroid cream[10,15,17,19,44]
Avoid greasy ointments on trunk and face, though skin on limbs will benefit	Greasy ointments may prevent moisture from escaping thus increasing the risk of superinfection[10,15,19]
Fissures	
Keep hands dry	Use gloves when hands need to be in water i.e. washing up Dry thoroughly when wet[10,15]
Protective footwear and covering of the fingertips Thick moisturisers/zinc oxide creams Bleach soaks Liquid glues cyanoacrylate (Superglue® Liquid Bandaid®)	Protection from and reduction of friction Prevents further damage and allows for healing Prevent infection by using diluted bleach soak for hands and feet Used to seal cracks and prevent them from worsening and reducing the risk of infection[10,44]
Oral antibiotics	May be considered if infection is present[10,20]

Assessment and management

As no treatment is entirely curative of paronychia and the periungual effects of EGFRI agents[19], management strategies are directed toward minimisation of the periungual trauma, reduction in inflammation, prevention of infection and elimination of excessive growth of granulation tissue[10]. Table 3 highlights the management of paronychia and periungual effects.

Table 3: Management of paronychia and periungual effects

Management strategies	Rationale/evidence
Avoid tight or ill-fitting shoes Wear gloves during household chores and cleaning	Minimise friction and pressure on the nail beds/folds Keeps hands clean and dry; less risk of infection and reduction of risk for periungual trauma[10,19]
Keeping nails trimmed though avoid excessive manicuring	Keeps the nail short and minimises trauma[10]
Creams	Drying paste with chlorhexidine, antifungal and steroid[19]
Antiseptic soaks	Reduces the risk of infection Using diluted bleach, or vinegar as prevention. Antibiotic solution if infection present[10,19]
Antibiotics (oral tetracycline)	Treatment of infection[19,44]
Non-steroidal anti-inflammatory medications	Pain management[19]

Trichomegaly

Trichomegaly is characterised by elongated, thick, stiff and curly eyelashes with up to 70% of patients reporting this side effect[14,44]. These changes can appear at any time from three weeks to eight months after commencement of intravenous EGFRI therapy[44]. The disorder is a result of the acceleration of the growing and resting phase of hair growth, resulting in a peculiar elongation and curling of the eyelashes[15]. Wu and colleagues describe the outer root sheath of the hair follicle as highly expressing EGFR, which leads to the differentiation of the hair[44]. Such disorganisation of the eyelashes can lead to discomfort from the lashes growing in awkward directions and can result in corneal abrasions and ocular complications[15,18]. The oncology nurse should ensure they provide the patient with education about the possibility of this complication and advise early medical attention before potentially serious injuries occur[18].

Table 4: Management of trichomegaly

Management strategies	Rationale/evidence
Trimming of the lashes	Careful trimming of the lashes can keep them at the appropriate length Plucking them when they are growing towards the eye[14,15,19-21]
Referral to an ophthalmologist	If eye injury or irritation is occurring, patient should receive a prompt referral to ophthalmologist to investigate the status of the eye surface and cornea[10,14,15]
Education to ensure patient vigilant regarding eye injury management	Education of the patient and significant others may assist in identifying adverse changes early[10,14,15]

Miscellaneous toxicities relating to intravenous EGFRI administration

Pruritus

Up to 50% of patients will experience pruritus[8,15,18], both during and after the appearance of the acneiform rash. If severe and unrelenting, this symptom may impact heavily on the patients' quality of life; therefore, it is vital that the health care team acknowledge and manage it[10,16,22]. Reduced cutaneous moisture is thought to contribute to the pruritus; therefore, the use of a thick moisturising cream on limbs and extremities and a lighter cream with colloidal oatmeal for the face is recommended[8,16,17,19] while avoiding ointments which may occlude the fissures and cause folliculitis[15,18]. Treatment of the underlying acneiform rash with antibiotic therapy is also a tool in the management of pruritus[10]. Additional strategies for the management of the EGFRI-related pruritus include wearing loose clothing, skin cooling and antihistamines (non-drowsy during the day and drowsy formulations at night)[10] although Grenon and Chan[17] suggest that gamma-amino butyric acid analogues, that is, gabapentin and pregablin may help[8,38].

Hirsuitism and hypertrichosis

Hirsuitism is described as an excess of body or facial hair (especially in women) located in a normal male hair pattern (that is, beard, top lip and chest)[42] and can be related to the administration of EGFRI medication. Interestingly, for male patients receiving an EGFRI there seems to be a reduced requirement for facial shaving, yet women experience an increase in facial hair, possibly linked to an interaction between EGFRI and androgen function[47]. Appearing after one or two months of EGFRI therapy, the excess hair does not necessarily diminish over time and is likely to persist throughout the EGFRI therapy trajectory[10].

Assessment and management

Whilst the literature does not recommend that women shave unwanted facial hair[20] temporary or permanent hair removal including bleaching, depilatory creams and laser therapy may assist[10]. Due to the likely insult to the patient's body image, education and support are highly recommended[10,18,44].

Hyperpigmentation

A post-inflammatory hyperpigmentation is often observed after the acneiform rash has abated and is aggravated by UV exposure or sunlight[20]. It is important to advise the patient to avoid sun exposure or use appropriate sunscreen and clothing when outdoors[8,19,47].

Telangiectasia

As a result of the inhibition of the EGFR signalling in endothelial cells of which the capillaries of the dermis are made, dilated blood vessels are more visible through the thinned skin[15] and often appear on the face, posterior ears and on the anterior thorax and limbs in areas where the acneiform rash is or has been[47]. Strategies to prevent aggravation of telangiectasia include limiting sun exposure and prompt and effective management of the acneiform rash when present[15,38,39]. Saegart and Van Cutsem[19] suggest that the EFGRI-induced telangiectasia will disappear gradually over months and that treatment for this condition is not necessary; however, the skin should be kept moist. Camouflage cosmetics may be used, although residual hyperpigmentation may persist[47].

Conclusion

The cutaneous toxicities experienced when a patient receives intravenous cetuximab or panitumumab are significant, contributing to considerable impacts on the physical, emotional and social dimensions of quality of life[12,13,17,40,41]. Assisting the patient to manage these effects is an important element of the oncology nurse's role[13,18,31] as an integral member of the interdisciplinary team responsible for care delivery to the cancer patient along their treatment trajectory[17-19].

Provision of patient education around the cutaneous toxicities encompassing preventive measures, early detection and intervention strategies are critical to achieving a reduction of symptoms and assistance with self-management and may be associated with an improved quality of life[10,16,18]. Multidisciplinary education in relation to the potential side effects of EGFRIs should result in improved support and better clinical outcomes for these patients[10,12,18,21,26].

Conflict of interest declaration

Marie Condon is a member of the MerckSerono Nurses Advisory Board for Erbitux (cetuximab).

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8 Whitington Avenue, Glen Osmond, SA 5064
Tel 0419 822 969 Email info@cnsa.org.au

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Clinical Nurse Consultant Gynaecological Oncology, Westmead Hospital, Westmead NSW 2145

Tel (02) 9845 5555 page 08503 Fax (02) 9845 8311 Email Letitia.Lancaster@health.nsw.gov.au

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