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In this issue

Editorial

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

Notes for contributors

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

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Editorial

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I am currently self-isolating for 3 days, having recently undertaken precautionary testing for the coronavirus. This has provided me with the valuable opportunity to reflect on how profoundly things have changed in the 6 months since our last editorial.

The world has changed from the one we knew in ways that few would ever have imagined; a health crisis on a scale that has not been experienced since the global Spanish flu pandemic of 1918–1919. This has brought with it a drastic change to how we live, work, interact with our families and socialise with our friends. Social isolation, home schooling and work 'pivots' – even bulk-buying of items we would never have previously thought essential – have become the new norm. What we now consider to be 'normal life' is extremely different to that experienced just a few short months ago.

In Australia, we have been incredibly fortunate that the cases of COVID-19 have been relatively low. Although every related death has been tragic, we have collectively managed to 'flatten the curve'. Furthermore, from many accounts, we have, as a population, managed to embrace kindness, compassion and consideration of others – attributes that, as nurses, we are very familiar with, yet which seem to have taken the world by storm.

In recent months nurses have attracted widespread public acknowledgement and admiration like never before. The UK and USA have, arguably, led this long overdue recognition by encouraging public displays of gratitude and appreciation. We have witnessed public applause and hero worshipping that has elevated the image of nurses to levels previously unknown. Yet, as nurses, we have done what we have always done and will continue to do in our roles as health professionals. We have been there for our patients, we have cared for them with respect and dignity, and we have advocated for and protected the vulnerable. We have demonstrated knowledge and skills and combined these with the compassionate care that every patient requires and deserves. Despite COVID-19, this has not changed.

This new-found public recognition of nurses, therefore, needs to be taken with caution. While rightly recognising the sacrifices and challenges that many nurses have recently faced in the midst of this pandemic, we must be careful not to reinforce traditional stereotypes. Depicting nurses as angels, saints and even super heroes does little but compound long-held misconceptions, thereby undermining the real essence of nurses' work and professional status. Compassion and kindness are essential to nursing, yet nurses also require intelligence, critical thinking ability and judgement. Yet, where have these traits shone in recent accolades?

As we think about future challenges, we, as editors, pose a challenge to you as readers of this journal. If you are passionate about cancer nursing and wish to contribute to the ongoing development of the cancer nursing profession, we invite you to consider becoming a peer reviewer of manuscripts submitted for publication. As well as playing an important role in maintaining the quality of the journal, being a peer reviewer provides the opportunity to share your expertise, develop your career and professional reputation, and keep up to date with new developments in the field of cancer nursing. If you are interested please submit a brief application as outlined in the advertisement in this issue.

As we continue to navigate these uncertain times, we encourage you to access the COVID-19 resources for cancer nurses available on the CNSA website. We also hope that you and your families stay safe and keep well.

The Editors

Call for peer reviewers

The Australian Journal of Cancer Nursing (AJCN) is a refereed biannual journal. It publishes high quality manuscripts regarding developments in research, education, policy, management and professional issues which are relevant to nurses and health professionals interested in cancer nursing and the delivery of cancer services in Australia.

The journal editors recognise the valuable contribution and essential role that peer reviewers have in maintaining the quality of manuscripts and ensuring the reputation of the journal. We are now seeking to expand our team of peer reviewers and expressions of interest are currently being sought by new team members. Selected reviewers will be matched with manuscripts relevant to their areas of experience and expertise. Editorial support and mentorship will be provided to new reviewers.

If you have an interest in cancer nursing, as either a clinician, academic, manager or policy-maker, and would like to contribute to the *AJCN*, please submit a short statement (approximately 1–2 paragraphs) outlining your qualifications and area(s) of expertise along with a brief CV to editor@cnsa.org.au.

Your statement should include:

- Full name.
- Preferred email address.
- Education – list of qualifications and institutions (e.g. degree, institution).
- Current position and place of employment.
- Detailed description of your area(s) of expertise.

We look forward to hearing from you soon.

Standardisation of systemic anti-cancer therapy (SACT) prescription forms: a pre–post audit evaluation

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Abstract

Introduction Clinical practice guidelines based on best available evidence and national safety and quality standards promote high quality and safe care.

Aim To review and standardise systemic anti-cancer therapy (SACT) forms in a 20-chair cancer centre to reflect Australian and international clinical practice guidelines.

Method A pre–post audit design based on Clinical Oncological Society of Australia (COSA) guidelines for the safe prescribing, dispensing and administration of systemic cancer therapy underpinned the project. The pre-audit (47 forms) provided a benchmark for SACT form improvements: 177 new forms were then developed over 18 months and implemented.

Results Pre-audit: 9/19 criteria were >70% compliant with best practice guidelines. Post-SACT implementation audit: 15/19 criteria were >70% compliant. The recent 2018 audit: improvements shown in 18/19 criteria.

Conclusion This nurse-led multidisciplinary initiative effectively standardised SACT charts with best practice guidelines, potentially reducing serious medication errors and facilitating a high standard of multidisciplinary patient care.

Background

Systemic anti-cancer therapy (SACT) is classified as a high-risk medication and is predominantly used in complex anti-cancer treatment regimens. SACT can cause fatal adverse toxicity events even when used at therapeutic dosages due to narrow therapeutic indices, complex anti-cancer treatment regimens, and the vulnerable cancer patient population[1,2]. Despite the known risks, medication errors related to incorrect prescribing, preparation and/or administration remain relatively common despite recent increased efforts to enhance patient safety[1]. Ranchon et al.[3] demonstrated in their prospective study of 6,607 antineoplastic prescriptions that 341 (5.2%) contained at least one medication error (total errors n=449). Of these errors, 436/449 were intercepted before the medication was administered to a patient. Prescription errors accounted for 91% of errors, with 13.4% of avoided errors potentially resulting in temporary injury and 2.6% in permanent injury.

The Pennsylvania Patient Safety Authority[1] analysed 1,015 medication error events associated with haematology and oncology outpatient departments over a 2-year period from June 2015 to June 2017. Medication events included antineoplastic drugs, SACT pre-medication drugs, opioids and anticoagulants. High alert medications – those that pose an increased risk of patient harm when involved in medication errors – accounted for 55.5% (n=563) of events; the most commonly prescribed being antineoplastic agents (94.3%, n=531). More than half (53.7%, n=545) of the events affected the patient and 43.3% (n=439) were intercepted before reaching the patient. Errors occurred most

frequently during the prescribing and administration processes. Car et al.[4] recruited 40 North West London cancer care clinicians to identify and prioritise perceived causal reasons for, and solutions to, medication errors in cancer care using a priority-setting approach. Thematic analysis revealed 20 distinct problems and 22 solutions. Twenty-six clinicians from the original cohort then ranked the composite list of perceived problems. Improved communication between healthcare providers, quality assurance procedures – during prescription and monitoring stages – and patient education were identified as key strategies for improving antineoplastic medication safety. The prescribing stage was identified as most vulnerable to medication safety threats. Banasser, Karpow, Gaunt and Grissinger[5] suggested that error reduction strategies in outpatient oncology clinics should commence with a risk assessment of medication use processes with a focus on communication and quality procedures during the prescribing process.

There has been a notable shift in the evidence-based international guidelines related to the administration of SACT. Well-designed, standardised, regimen-specific SACT order forms decrease potential errors by organising treatment information in a clear, consistent and uniform format[6]. The use of computerised prescriptions is now recommended as best practice to reduce the risk of adverse events and that, in lieu of computerised prescribing, standardised, pre-printed forms must be used to maintain consistency, and that handwritten orders are unacceptable[6–11].

Leung et al.[12] developed an evidence-based practice guideline for the safe administration of SACT and management of preventable adverse events for use in the Canadian Province of Ontario. The guideline was influenced by the clinical expertise of the working group members and multiple international SACT administration guidelines including COSA's guideline for the safe prescribing, dispensing and administration of systemic cancer therapy[9], and eviQ's timeout procedure checklist[13] and clinical safety procedure[14]. The quality of the Australian eviQ[13,14] and COSA[9] guidelines and other international guidelines was evaluated by the working group using the Appraisal of Guidelines for Research and Evaluation (AGREE) II Tool[15]. The guidelines were rated highly across all domains[12]. Of note, the COSA guideline for the safe prescribing, dispensing and administration of systemic cancer therapy recommends that a fully validated electronic prescribing system should be utilised for the prescribing of SACT wherever available; if not, pre-printed prescriptions should be used[9].

In Australia, the safe administration of SACT is guided by the COSA guidelines for the safe prescribing, dispensing and administration of systemic cancer therapy[9] and eviQ's online evidence-based, consensus driven cancer treatment protocols and information for use at the point of care.

Australian healthcare organisations are required to undergo mandatory accreditation, the recognition by a healthcare accreditation body of the achievement of eight quality and safety standards through an external peer assessment process. The National Safety and Quality Health Service (NSQHS) standards are developed by the Australian Commission on Safety and Quality in Health Care in consultation with the Australian government, states and territories, the private health sector, clinical experts, patients and carers[16]. The primary aim of the NSQHS standards is to: protect the public from harm, improve the quality of health service provision; and support a quality assurance mechanism that tests whether relevant systems are in place to ensure that expected standards of safety and quality are met. The delivery of SACT is mandated by the NSQHS standard 4, medication safety[16], that requires SACT order charts to reflect current best practice guidelines.

Consistent with other national and international tertiary cancer treatment centres, SACT at the study site is constantly evolving with the introduction of immunotherapies and targeted therapies which are transforming treatment regimens for many cancers. Prior to study commencement it was observed that current SACT charts did not meet minimum Australian and international best practice standards for the delivery of SACT.

Ethical issues

Approval to conduct this nurse-led study was granted by the study site's Human Research Ethics Committee. Approval was based on a waiver of consent and contingent on the analysis and presentation of aggregated data ensuring patient anonymity.

Plan, Do, Study, Act (PDSA) model for service improvement

The Plan-Do-Study-Act (PDSA)[17,18] framework guided development and standardisation of SACT prescription forms. Stages of the PDSA cycle are:

- Plan – determine the change to be tested or implemented
- Do – carry out the test or change
- Study – based on the measurable outcomes agreed before commencement, collect data before and after the change and reflect on the impact of the change and what was learned
- Act – plan the next change cycle or full implementation[19].

Prior to implementation, three guiding questions were considered:

- What are we trying to accomplish (aim)?
- What measures of success will be used (audits)?
- What change concepts will be tested (best practice SACT prescription forms)?

Plan

The study was conducted in a 20-chair outpatient cancer centre located within a large 507-bed private tertiary teaching hospital in the southern corridor of the Perth metropolitan area in Western Australia. The study site has witnessed a steady increase in patient presentations over recent years from 4,500 in 2009/10 to >15,000 in 2017/18, with 10,384 episodes of anti-cancer treatment provided in 2018.

The SACT charts used prior to the study commencement were developed in 2013 prior to the introduction of immunotherapies, targeted biological therapies and current Australian and international best practice SACT guidelines. This study aimed to review, develop and standardise SACT prescription forms to reflect current national and international best practice.

Do

In 2015 a multidisciplinary committee was convened to review 47 SACT order charts in use pre-study. Committee membership comprised cancer nurses, oncology pharmacists, oncologists and haematologists. SACT charts were compared against the Cancer Institute New South Wales eviQ[14], the National Comprehensive Cancer Network (NCCN)[20] and the British Columbia Cancer agency (BC Cancer)[21] protocols. The team agreed that development of individual charts for each treatment regimen (n=224) was required to reflect current best practice and reduce the risk for adverse medication errors. A compliance audit tool based on the COSA guidelines for the safe prescribing, dispensing and administration of systemic cancer therapy[9] was developed and used to audit 50 SACT charts in June 2015. SACT charts were randomly selected and audited over a 1-week period to identify inconsistencies with best practice.

Study

Baseline audit results were disseminated and reviewed by all committee members (Table 1). In consultation with the multidisciplinary team, the study centre pharmacists assumed responsibility for the process of revising 47 existing, and developing 177 new, SACT prescription forms using the Cancer Institute NSW standard cancer treatments (eviQ) guidelines[14], the NCCN[20] and the BC Cancer chemotherapy guidelines[21] protocols as reference tools. Two hundred and twenty-four SACT forms were approved for circulation and patient use in the cancer centre over an 18-month period between June 2015 and November 2016. Each SACT prescription chart was peer reviewed by oncologists, haematologists, the nurse unit manager (NUM) and an external lead pharmacist from a non-oncology department within the hospital. The hospital's Medication Safety Committee advised that due to the specialised nature of the SACT prescription forms, approval from the cancer centre team was sufficient to proceed with the implementation of the new forms. Prior to implementation in November 2016, education was primarily provided to the multidisciplinary team by the lead oncology pharmacist via face-to-face meetings with oncologists and haematologists to explain the changes to the SACT prescription forms and the proposed implementation process. All other staff were notified electronically via email with the same information and requested to provide feedback to the multidisciplinary committee. This feedback process continues as an ongoing process.

Act

In February 2017 a repeat audit using the same audit tool was undertaken with 50 randomly selected SACT charts over a 1-week period (Table 1). The results were disseminated to all oncologists, haematologists, pharmacists and nursing staff.

Based on the four areas with the lowest compliance, a number of interventions were employed. Further education was provided by the chief pharmacist to oncologists and haematologists to address key deficits identified by the audit via one-to-one discussions. These physicians were encouraged to initial and date treatment dose changes and to clearly identify the treatment cycle, the most common deficits identified by the audit. Nurses were requested not to accept incomplete SACT order charts.

Results

Table 1 presents pre- and post-audit results. A compliance rate of <70% requires immediate action; compliance between 70% and 85% indicates a need for improvement, and compliance >85% signifies good compliance with best practice guidelines.

The pre-audit conducted in 2015 showed that only three domains illustrated >85% compliance with current best practice guidelines. More than 50% of domains showed a compliance of <70% and highlighted a need for immediate action since they indicated potential for serious adverse events for patients receiving SACT. During the 18-month period when SACT charts were being revised, oncologists and haematologists were educated by the lead pharmacist regarding the COSA best practice guidelines and expectations of them as prescribers of anti-cancer therapy.

Results of the second audit performed in 2017 after the standardised charts had been in use for 3 months showed an improvement, with nine domains achieving good compliance and only four domains illustrating poor compliance. The 2018 audit showed the cancer centre had achieved good compliance in 14 domains, while the four areas with poor compliance showed an overall improvement and highlighted areas where the cancer centre needs to improve. The only area which has shown a decrease in compliance between the 2017 and 2018 audits is the accurate height, weight and body surface area (BSA) domain. This is concerning as accurate dosing of anti-cancer therapy is dependent on accurate BSAs. There is the potential for patients to be underdosed, with resultant compromise of success of the therapy, or overdosed and experience potentially fatal side effects[3]. BSA is initially calculated by the prescribing doctor and

Criteria	Compliance Jun 2015	Compliance Feb 2017	Variance ▲/▼	Compliance Aug 2018	Variance ▲/▼
UMRN sticker with hospital number, name, DOB	98%	98%	nil	98%	nil
Current height, weight and accurate BSA	42%	89%	▲ 47%	72%	▼ 17%
Computer-generated prescription (not handwritten)	82%	82%	nil	88%	▲ 6%
If handwritten, is the drug and dose clear and unambiguous?	50%	86%	▲ 36%	96%	▲ 10%
Is the drug dosing clear and do drug doses have appropriate measurements?	63%	78%	▲ 15%	92%	▲ 14%
Are the drugs prescribed clearly in the correct order?	80%	88%	▲ 8%	100%	▲ 12%
Has written consent been obtained?	0%	0%	nil	0%	nil
Is the chart signed and dated?	77%	96%	▲ 19%	100%	▲ 4%
Is the name of the regimen clear and appropriate?	61%	88%	▲ 27%	88%	nil
Is the cycle number clearly written?	49%	55%	▲ 6%	68%	▲ 13%
Is the route of administration clear?	89%	92%	▲ 3%	98%	▲ 6%
Is the tumour type and stage stated?	59%	74%	▲ 15%	92%	▲ 18%
Is the infusion rate clear?	77%	80%	▲ 3%	98%	▲ 18%
Is the diluent/compatible fluid clearly recorded?	75%	78%	▲ 3%	98%	▲ 20%
Are allergies clearly stated?	92%	94%	▲ 2%	98%	▲ 4%
Are dose changes initialled and dated?	2%	1%	▼ 1%	13%	▲ 12%
Are 'crossings off' initialled and dated?	4%	0%	▼ 4%	13%	▲ 13%
Are the required laboratory tests documented?	70%	88%	▲ 18%	89%	▲ 1%
Is supportive therapy charted unambiguously?	43%	77%	▲ 34%	98%	▲ 21%

UMRN = unit medical record number, DOB = date of birth, BSA = body surface area

checked by the pharmacist, although nurses check the patient's weight at each cancer centre visit. If the weight has changed, the nurse will recalculate the BSA and inform the prescriber. Nursing staff will continue to receive education around completing this calculation and support to return the chart to doctors if the dosing is incorrect.

Of note, whilst 'obtaining written consent' was recorded as 0% for each audit, this is because verbal, not written, consent was gained from patients during the period covered by the audit. Since 2018, the practice has changed to ensure the written consent form is kept with the patient's SACT prescription.

A patient safety analysis of 1,015 medication errors reported in the Pennsylvania Patient Safety Reporting System from outpatient haematology and oncology clinics[5] illustrated that dosage errors were mostly attributed to inaccurate patient weights; this was also a finding of our quality initiative. Current patient information is therefore essential to guide accurate prescribing.

Currently, in 2019, the standardised SACT charts remain in use within the cancer centre. The success of this initiative has prompted standardisation of SACT charts across all of the organisation's Western Australian divisions who administer SACT, with the new chart considered the benchmark.

Discussion

Adherence to best practice SACT guidelines ensures safe and high quality care for patients receiving anti-cancer therapies in an outpatient cancer setting. This nurse-led study has demonstrated how a systematic approach has produced clinically significant improvements in multidisciplinary practice through implementation of standardised SACT prescription forms. Importantly, this change in practice has reduced the potential for serious medication errors.

Notwithstanding the positive outcomes of this study, improvement is still required in some areas. It is proposed that continued application of this collaborative multidisciplinary approach can facilitate improvement in a number of ways. It is essential the cancer centre adopts a strong culture of safety and quality. We recommend that cancer nurses, oncologists and pharmacists are provided with continuous education about the requirements of SACT prescription charts as per current best practice national and international guidelines. Nurses and pharmacy staff must be encouraged and supported to 'refuse to accept and use' incomplete SACT prescription charts. The cancer centre is also committed to performing an annual audit and review of the forms in order to standardise SACT forms and minimise the risk of medication errors and patient harm. Electronic SACT prescribing is due to be introduced to the cancer centre in the near future and will further embed the culture of safety and quality we strive to maintain.

Recommendations

- Perform an annual audit and review of SACT prescription forms.
- Maintain multidisciplinary team education to ensure best practice prescribing and administration of SACT.;
- Continue peer review of SACT prescription forms as new SACT become available.
- Ensure SACT prescription forms are used as the benchmark for the organisation's other Western Australian cancer centres to prevent and/or minimise medication errors.
- Continuously review both actual and near miss medication errors in order to implement further risk prevention strategies to reduce errors for this high risk population.

Conflict of Interest

The authors declare no conflicts of interest.

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Cancer Nurses Society of Australia

What cancer survivorship services do young people want?

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Abstract

Aim To identify experiences of young cancer survivors and their perception of optimal components of survivorship care and wellness programs.

Background Most young people survive their cancer diagnosis and are then at risk for long-term negative consequences. Survivorship care is important, but there is little evidence to inform optimal service models.

Methods Semi-structured interviews were conducted with adolescents and young adults (15–24 years). Content analysis was used to identify themes.

Results Sixteen young people participated. Three major themes are described: concerns after treatment; after treatment services; and perceptions of a wellness survivorship program. Within each theme, further subthemes highlighted the difficulties young people face when trying to return to normal life. Fear of cancer recurrence and a need for greater coordination of support and services were the highest concerns.

Conclusions: Findings highlight the need for an individualised approach to survivorship care that engages and empowers young people as partners in their own healthcare.

Introduction

Cancer survivorship is considered the next tsunami to affect health services, with an exponential number of people surviving treatment, many of whom have ongoing needs for healthcare related to their cancer[1]. In Australia, up to 89% of adolescents and young adults (AYA) aged 15–24 years reach 5-year disease free survival[2,3].

Common to all cancer survivors, AYA experience a wide range of long-term negative effects after cancer treatment. Problems with mobility and limitations with usual activities are reported by up to 43% of all cancer survivors, and 12% report moderate to extreme levels of anxiety and depression[4]. The AYA population is more likely to also suffer psychosocial problems such as: altered sense of identity; changed relationships; challenges to body image, sexuality and fertility concerns; impacts on education

and employment with financial consequences; concerns about cancer recurrence which can manifest as a preoccupation with death and dying; and generally a less positive outlook on life[4–6]. Importantly, compared to AYAs with no history of cancer, AYA cancer survivors are also more likely to have a higher prevalence of chronic disease (14% vs 7%), disability (36% vs 18%), poor mental (20% vs 10%) and physical health (24% vs 10%)[7], and lower quality of life[8].

After completion of cancer treatment, ongoing routine surveillance and support in Australia is generally oncologist-led. This medical assessment includes risk of cancer recurrence or new cancer development, review of previous cancer therapies, and management of comorbid conditions[9]. This surveillance model of survivorship care, however, does not address all the after effects of cancer treatment. Attention to supportive care, lifestyle and health-related behaviours are also important to manage the physical and psychological effects of cancer and cancer treatment[10].

The needs of AYAs during and after cancer treatment are further complicated by the need to simultaneously navigate the social and developmental transitions of adolescence. It is recognised that the biggest challenge for this population is the immediate time following completion of active cancer treatment, when the intensive support provided during this time ceases[11]. When treatment ends, young people report feeling unprepared, concerned about managing their ongoing health needs, uncertain about relationships, education, employment, and lacking the confidence to plan for the future[11,12].

It is imperative we strive to improve outcomes for this group; however, little research has been undertaken to examine the effects of different models of care after cancer treatment, nor young people's preferences for post-treatment survivorship care[13]. Without this evidence, we don't know the best way to provide services and there is little impetus to change the way cancer services are delivered. Research and evaluation in this area is therefore critical to the successful design and delivery of sustainable, flexible and cost-effective survivorship care[13,14].

Well-designed models require an understanding of the clinical issues, the existing health system, and the processes required to integrate new systems[15,16]. Importantly, new models of care should also be informed by AYAs themselves as partners in their own healthcare. As part of a larger project to develop a new survivorship model of care, the aim of this research was to identify experiences of young cancer survivors and their perception of the optimal components of survivorship care and wellness programs.

Methods

The study was informed through discussions with the Queensland Youth Cancer Service's (YCS) Youth Advisory Group (YAG)[17]. The YAG consists of young people whose lives are affected by cancer. The role of the YAG is to advise on health service planning, delivery and evaluation. Through discussions with the YAG, survivorship care was identified as a priority area for research. The concept of a wellness program was discussed, where young people could access a range of resources and services to support recovery after cancer treatment. The YAG identified important issues to consider such as preferences for both group and individual services, and the need for equity of service in regional areas. These discussions informed development of a semi-structured interview guide which was endorsed by the YAG (Appendix 1). Qualitative methods were used to explore the perspectives of AYA regarding their experiences of cancer treatment and perceptions of wellness and survivorship needs after treatment.

Setting and sample

Eligible participants were those aged 15–25 years at the time of a diagnosis for any cancer. We chose this age range as this is the range for referral to YCS in Australia. Participants were identified through a database managed by the Queensland YCS network which links five major tertiary cancer centres in the state and provides specialised services to AYA. We excluded patients who were not expected to survive the next 12 months. To maximise clinical and demographic diversity, purposive sampling was used to recruit patients with different diagnoses, ages, and those who had received treatment across both metropolitan and regional areas. The list of eligible patients was screened by YCS cancer care coordinators in each cancer facility before being approached by the researchers; cancer facilities included those located in Townsville Hospital, the Gold Coast University Hospital, Royal Brisbane and Women's Hospital, Princess Alexandra Hospital, and the Queensland Children's Hospital. The researchers then explained the purpose of the study and obtained informed consent. In all, 30 participants were approached.

Interview procedure

The interview was scheduled for a mutually agreeable time and undertaken either face-to-face, or via telephone, depending upon the participant's location and preference. Each interview was conducted in a conversational style, using the interview guide as a structure. Questions were open-ended and addressed the participant's experiences of cancer treatment, their needs, ways of coping, and use of support resources and services. Participants were also asked about their perceptions of survivorship services, what they thought was needed, and if they would access a wellness program. The interviews were undertaken between September and December 2018. Interviews were audio-recorded and then transcribed verbatim by a professional transcription service.

Analysis

Audio recordings of the interviews were listened to whilst simultaneously reading the transcripts to ensure accuracy of

the transcription. Transcripts were then imported into NVivo™ software to aid organisation of the analysis. Content analysis was used to organise and elicit the latent and manifest themes within the data[18]. A preliminary coding structure was agreed upon by NB and CC which included deductive codes from interview questions. Transcripts were then openly coded by both researchers allowing for further emergent themes. The final coding structure was agreed upon through discussion, and data within codes were grouped into a hierarchy of themes[19]. Matrices were developed to enable coded data to be compared across the sample. Manifest data were subjected to counts and are presented as proportions of participants reporting a particular experience or perception. The latent (hidden or unsaid) meanings and divergent experiences were identified through immersion in the text[20]. Throughout the process, transcripts were re-read, and codes, themes and concepts were iteratively discussed.

Ethical considerations

All participants voluntarily participated and were assured their privacy and confidentiality would be respected. The study protocol was approved by the local Human Research Ethics Committee (HREC/18/QRCH/104).

Results

Of the 30 potential participants approached, 10 declined an interview and we were unable to find a suitable time for four. Thus 16 participated in the interview. Reasons for declining to participate included being "too busy", "just not keen" to "I don't want to re-visit that very difficult period". Demographics of participants are presented in Table 1.

In this report, we present the results regarding three major themes: concerns after treatment; a wish list for after treatment services; and thoughts about a wellness survivorship program. A summary of counts for each subtheme are presented in Table 2. Subthemes that were described by four (25%) or more participants are further discussed and presented with supporting quotes.

Table 1. Characteristics of participants (n=16)

Characteristics	n	%
Gender		
Male	10	63%
Female	6	38%
Age at time of study		
15–19	3	19%
20–25	13	81%
Cancer type		
Leukaemia	7	44%
Lymphoma	3	19%
Pituitary germ cell	1	6%
Brain cancer	2	13%
Carcinoma	1	6%
Ewing's sarcoma	1	6%
Rhabdomyosarcoma	1	6%
Treatment*		
Chemotherapy	16	100%
Surgery	5	31%
Radiotherapy	5	31%
Immunotherapy	2	13%
Haematopoietic stem cell transplant	5	31%
Type of hospital		
Public adult hospital	8	50%
Children's hospital	8	50%
Location of residence		
City	8	50%
Regional or rural	8	50%
Currently working or studying		
Attending school/university	6	38%
Working and university	2	13%
Working	5	31%
Not currently working or studying	3	19%

*Does not total as multiple treatment modalities received

Concerns after treatment

Integrating back to normal life with a changed identity

The difficulties integrating back into normal life were of high concern for nine (56%) participants. This appears to be complicated by a changed sense of identify after cancer treatment that AYA were unsure of how to process. Some were unsure about disclosing their cancer diagnosis. There was fear of rejection from potential partners, others didn't know how or if they should tell new employers. They reported feeling different from others and unsure about fitting back in with their peers. One participant likened his experience to that of a prisoner leaving jail:

> *I've never been to prison but [you could liken it to] a chemotherapy-type thing. You're in hospital. You're not in a comfortable environment. You're constantly being threatened or you're not eating nice food. Once you get out, people see you a bit differently, you know? You're seen a bit as a criminal is, – 'are they going to hurt me'? You see a cancer patient, 'okay, if I touch them, is their arm going to fall off'? –* #9, male, 22 years.

Others found it difficult after treatment completion with the change in priorities; their own health was no longer a great concern to either their healthcare team or the others around them. For one young adult, whose treatment spanned over 5 years, this was difficult; their identify was caught up in being a patient.

Table 2. Counts of categorised themes and subthemes (n=16)

	n	%
Concern after treatment*		
Integrating back to normal life	9	56%
Fear of recurrence	6	37%
Physical health, fitness and nutrition	3	19%
Education and work	3	19%
Regain control of life	3	19%
Relationships and fertility	2	13%
'Wish list' for after treatment services		
Co-ordinated support and information	7	44%
Psychological support to find the new normal	3	19%
Survivorship plan for follow-up	1	6%
Education and vocation support	1	6%
Fertility services	1	6%
Thoughts about a wellness survivorship program		
Not needed/wouldn't access	7	44%
Would access if one-on-one services provided	3	19%
Would depend on what is offered	4	25%
Would definitely access	2	13%

*Does not total as some participants nominated discussed multiple items

> *I've found in my last two transplants, one of the hardest times is getting back into normal life. It's the after effect because everything is sort of provided for you, you're the number one priority, you're this, you're that, and you go back into what is classified as the 'real world'. Normality, and it's not the case, it's not the same. You're not the primary focus anymore, you need to think about other people and at the same time, think about what you want* – #10, male, 22 years.

Integrating to normal life was also difficult for some because of the physical after effects of treatment. While they may no longer look unwell, with their hair re-grown and their weight improved, they didn't feel like their former selves, nor were they sure how to go about recovering. Fatigue and 'chemo brain' in particular were reported as an enduring concern after treatment.

> *Chemo foggy brain, well it feels like that lingers for about I would say 12 months after as well. So, you sort of, you're trying to get well but then you're not sure what to do or how to get well* – #11, male, 18 years.

Even for those who didn't have physical or emotional difficulties, integrating back to a normal life was not straight forward:

> *It felt like we were just, like, left, like they'd cared for us so much, like, from diagnosis to, like, end of treatment, that I feel like we were left on our own. We didn't really know what to do. Like, how do you transition back to normal life? Because it was so long. Just, like mum and dad both stopped working and were looking after me. And it was just hard to go back to what we used to live like* – #14, female, 21 years.

Fear of recurrence

Another frequently reported concern after treatment was fear of recurrence. In our sample, six (37%) AYA reported this as a high concern. Some tried to rationalise this fear, and all acknowledged that this fear was what made the mental aspect of a cancer diagnosis more difficult than the physical:

> *It's torturous on the old mind... thinking, has it gone? Is it going to be better? What's going on? Even in the car now, I put the wrong setting on my air conditioning. I put the foot one or the face one on, instead of just the air con that blows on your face, and the air con starts blowing on my leg, and I thought, oh, crap. My leg's itchy. It's back. You know what I mean? Because, that was one of the symptoms* – #9, male, 22 years.

> *I guess your biggest concern is getting sick again... because you're actually not getting treatment...* – #13, female, 22 years.

> *So that's definitely always on my mind, that's definitely been the toughest thing to deal with at the moment, is thinking of what if it comes back. Yes* – #6, male, 20 years.

Wish list for after treatment services

Co-ordinated support and information

Regaining strength and fitness was a high priority for AYA, and an area where more support was wanted. While services may be available, either the cost or the processes required to access services was seen as a barrier:

> *I think for me I would really love to get a good routine with a physio. Because since I've been sick like my back's gone, it's really weak in my bones because of steroids. Yes, I struggle with that... that's a big one for me. Because I used to be a very healthy person, so not being able to do squats or lunges really.... brings me down. But I have to request it through my doctors. I feel like if I had an appointment once a week or once every two weeks it would just help me get back on my feet a bit better* – #6, male, 20 years.

> *So there needs to be like a middleman to liaise with the doctor and then get the information from them and then they can maybe like contact any relevant people to get other information. Yes, and then like some, like classes about, nutrition and health advice would be useful after you've finished treatment and you're sort of wanting to improve your health after that, to get advice about that. And like someone to talk to about questions you might have after you've had treatment* – #13, female, 22 years.

Some highlighted not having anyone to go to for advice or questions after completing treatment. For others, services were available, although only as part of a study or through strict referral criteria. These weren't flexible and, having just completed

cycles of schedule treatment, as a young person, more routine was not wanted:

> *I was offered a fitness programme for the end of this year, and that was just to resume sort of exercise rehabilitation. It's obviously the main thing that I was wanting, but my issue is that because it was part of a study, I had a fixed frame of, be there for the first week, the seventh week, and the twelfth week. Whereas now post-treatment, I'm sort of anticipating on travelling around the world now first for a year. So, whilst I would love to have done that, I would have preferred if there was just flexibility, just sort of me there at the end. Yes, because I'm just at this end of the phase I'm not going to be trying to get back to a scheduled life* – #4, male, 21 years.

This highlights the complexity of balancing survivorship needs with normal life needs and the liminality an AYA with cancer faces.

Thoughts about a wellness survivorship program

Seven participants (44%) stated they would not access a survivorship program focussed on wellness. Some felt that while such a service may be beneficial for others, they said it would not suit them. Reasons included wanting to avoid potential group situations where negative experiences may be discussed, and that needs were already met by existing services, friends and family; others felt they had no need for such a survivorship program:

> *Yes, just because I've had my treatment for so long and like I've been lucky that [my treatment] has been kind of good, so I've been able to get back [to normal] and just, like all my sport and work. So just knowing me, even if it were available, I would have wanted to do it on my own anyway* – #1, Male, 20 years.

Other participants suggested various combinations of services and factors that would make a service acceptable. There was great variation; some preferred one-on-one services, others group-based, some wanted to meet others who had been through treatment and others were not sure. Video conferencing was acceptable to most participants, although all agreed face-to-face was preferable. There was a difference of opinion on where a service should be located, e.g. hospital-based or community-based, what services should be available, and how long such a service should be offered for. These findings highlight the need for an individualised approach to survivorship care and that a one size fits all model is not appropriate nor acceptable.

Discussion

This study sought to identify the experiences of young people after cancer treatment and their perceptions of the optimal components of survivorship care and wellness programs. Our findings identified young cancer survivors were concerned with how to return to normal life, fears of recurrence and the desire to regain physical health. These findings are congruent with research reported internationally[5,21]. For these concerns to be addressed, the young people in this study discussed the need for a coordinated approach to survivorship care that is flexible and highly tailored to individual needs.

A significant proportion (44%) of AYA in our study stated they would not access a survivorship wellness program, despite agreeing that such a service would be beneficial for others. These young people were happy to continue oncologist-led medical follow-up but did not want their general health and wellbeing to be the concern of a cancer survivorship program. These findings highlight the complexity of developing services that not only meet the health needs of AYA cancer survivors, but that are also acceptable to young people. It is understandable that, following treatment, individuals may want to 'move on' and thus distance themselves from cancer services in an effort to return to their lives as they were before cancer. Reluctance to engage in survivorship services has also been described in adult cancer survivors and was attributed to patients downplaying problems, or not understanding that treatment is available[22]. Young people have the longest time to live with the consequences of cancer and cancer treatment, resulting in a higher long-term impact and known risks for treatment-related late effects[23]. At this stage in life, a young person may not anticipate their future needs and consequently may not realise the importance of survivorship care. Transitional survivorship care that focusses on adjustment may be more preferable to programs focusing on physical or psychological health.

By the year 2040 in Australia, there will be an estimated 6000 children under 15 years living with or beyond cancer, 20,000 adolescents and 41,000 young adults aged under 40 years[24]. While survival after cancer is increasingly likely, so too are the negative consequences of cancer that can limit the young person's ability to reach their full potential to contribute to society. Studies have identified four out of five young survivors experience at least one late effect and 50% experience significant sequalae; by the age of 40 years, most will have at least one chronic health condition[25,26]. Additionally, the risk of secondary cancers in those diagnosed before age 25 years is high[21,27]. Addressing the survivorship needs is therefore an imperative direction for health services and a public health concern. Indeed, there is an increased risk that instead of being active contributors to society, young survivors with unmet needs may continue to be reliant on the health and social systems[28]. For these reasons it is important we address survivorship needs proactively and consider the ongoing consequences of cancer not just for the individual but also for the health system and the wider community.

Internationally, services are starting to focus on the survivorship needs of this population[4,23,29,30]. There is a paradigm shift from measuring clinical outcomes to a greater focus on recovery and measuring experiences for survivors based on individual needs

and preferences[31]. A risk-based approach for after treatment care is advocated for, and wellness-centred approaches may offer a way to provide education and support self-management while also addressing the specific issues AYA face in regards to sexuality, body image, relationships, fertility and education/vocation[21]. Further research is required to develop and test risk stratified models of survivorship care that address health needs, engage and empower young people and, as highlighted here, are acceptable. Developing such responsive health services requires an understanding of the demand for services, and this study contributes to the limited evidence base.

Young people in this study made suggestions for various models of care, including the use of technology to connect survivors with each other and with healthcare professionals. The use of technology holds promise for both accessing specialised support from distant locations, and also connecting back to local communities from metropolitan areas[32]. Emerging novel examples include using online video-based cognitive behavioural therapy (CBT) for youth cancer patients[33]. Further research could investigate the potential of using technology to connect patients, specialists and primary care teams. Other models of care that require further development and evaluation include nurse-led survivorship clinics and peer support models[34].

Limitations

There are several limitations to consider with this study. Our sample size was small, and there were a number of young people who did not want to participate who may have added further depth and understanding to this issue. We had equal numbers of adolescents and young adults, which reflects the population referred to Queensland YCS, but not the population of AYA diagnosed with cancer; there are more young adults diagnosed with cancer than adolescents, a substantial number of whom receive treatment in private hospitals which are not included here. We did, however, include young people from diverse locations, across multiple institutions, and with different experiences, and our sample size is typical of other qualitative studies[35,36].

Conclusion

We identified the experiences and concerns of young people following cancer treatment. There was a strong desire to return to normal life as quickly as possible. While some participants felt their needs were met, others needed greater information and coordinated support at this time. Given children and young people are the population with the most potential to contribute to the economic growth of a nation, a continued and sustained focus on improving services for this group is warranted. Not only will this have positive societal effects, services may ultimately also prove cost-effective.

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Conflict of Interest

The authors declare no conflicts of interest.

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Appendix 1. Semi-structured interview guide

ARCHWAY interview guide: interview question prompts

What has been your greatest concern after cancer treatment?

- Consider general physical and psychological health, education, finances and relationships.

What types of services are needed to support these needs?

Who should provide these?

- GP, cancer service, other community service, cancer survivorship centre?

What type of after cancer treatment or follow-up was provided to you?

- Hospital, GP, other?
- Have you tried to source information/services yourself to address this need?

Improving care in the future

Wellness program

There is recognition that cancer treatment focuses on illness and the things that are needed in life to be well are not always addressed. A focus on wellness rather than illness is an opportunity to reframe the experience, emphasise the future, and set realistic goals to attain optimal wellbeing.

If we were to develop a wellness program, what are the types of activities, information or services that you think would be important in the program?

Prompts:

- Managing worry.
- Information about treatment or side effects.
- Concerns with fertility.
- Getting back to work or school.
- Practical issues.
- Issues with relationships.
- Meeting other people the same age.
- Staying fit and active.
- Diet and nutrition.
- Complementary or alternative treatments.

How do you think an ideal program would be delivered?

- E.g. in a group setting?
- One-on-one regular consultations?
- Telephone?
- Written materials?
- A program delivered over a specified time period?
- Drop in centre?
- Online resources/chat?
- Opinions on use of apps, chat features, videoconference, text?

Where is the best place for a wellness program for young people with cancer to be run from?

- In the hospital where treatment was given?
- In the local community?
- In a GP practice?
- In a setting away from hospital services?
- In a dedicated cancer survivorship centre?

For people living in rural areas, is videoconferencing a suitable way to receive services?

How long do you think a wellness program should be available for, for people who have received cancer treatment?

Who should deliver the wellness program?

- Nurses, social workers, psychologists, leisure therapists, teams of multi-professionals with different skills?

What things should we consider to make a program acceptable for young people to attend?

Thinking back over your experiences, do you think you would have accessed support via a wellness program if it were offered to you?

Are there any other ideas or issues you would like to talk about today?

Cancer Nurses Society of Australia

Implementing evidence-based supportive care for patients with skin toxicity associated with epidermal growth factor inhibitors in an ambulatory care setting

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Abstract

Background Epidermal growth factor receptor inhibitors (EGFRI) cause skin toxicity in the majority of patients who receive them. Evidence-based guidelines aim to reduce the severity and duration of skin toxicity which causes physical discomfort and impacts negatively on patients' quality of life.

Methods A pre/post-audit design was utilised at an ambulatory cancer care centre in a tertiary metropolitan hospital. Data were collected and audited from January 2018 to December 2019.

Results Documentation for 16 patients was reviewed against best practice recommendations. Barriers to evidence implementation and strategies to improve supportive care were identified and implemented. A post-implementation audit of 13 patients demonstrated that implementation strategies improved the delivery of supportive care.

Conclusion Targeted nurse education and dermatological toxicity-specific documentation are effective strategies for improving the implementation of evidence-based supportive care for patients with EGFRI skin toxicity.

Background

Epidermal growth factor receptor (EGFR) is essential for normal skin structure and function. It is normally expressed in a variety of epidermal cells such as undifferentiated, proliferating keratinocytes which are found in the basal and suprabasal layers of the epidermis of the skin[1,2]. The role of EGFR includes stimulation of epidermal growth, inhibition of differentiation and acceleration of wound healing[3]. EGFR expression is an important feature of normal skin development and assists in the normal function of skin, sebaceous glands, sweat glands, hair and nails[4]. EGFR is known to be over-expressed in many solid tumour cancer cells, including colorectal cancer, head and neck cancers, lung cancer, breast cancer and pancreatic cancers[2,5–7].

Epidermal growth factor receptor inhibitors (EGFRIs) target the over-expression of EGFR in specific cancer cells by blocking the normal receptor pathway to reduce tumour growth[3-6,8]. This blocking mechanism disrupts the normal expression of EGFR causing an inflammatory response and subsequent cutaneous injury; it is the inflammatory response that commonly causes dermatological toxicity in patients receiving EGFRIs[1,2]. There are two classes of EGFRI, specifically monoclonal antibodies and tyrosine-kinase inhibitors[2,8]. Monoclonal antibody EGFRI treatments have improved outcomes for advanced cancers with associated progression free survival, particularly in metastatic colon cancer. Two such drugs are commonly administered intravenously in the ambulatory care centre, Cetuximab

and Panitumumab[2,3,5,9]. Despite the known benefits of this treatment, it is estimated that greater than 80% of patients receiving anti-EGFR therapies experience skin toxicity[3,5,8,10–13]. Skin toxicity in patients receiving this treatment typically presents as a papulopustular rash, dry skin, pruritus and paronychia and symptoms are severe in 10–20% of patients[3,5,9]. The intensity of skin toxicity varies between individuals; however, the reason for the significant variability of toxicity is not known[9].

Due to the impact of skin toxicity, treatment with EGFRIs is frequently modified, discontinued or, in some cases, ceased altogether, thus negatively impacting the efficacy of treatment and potential subsequent progression free survival[2,5,9,14]. EGFRI skin toxicity also impacts on patients' quality of life and can have a profound psychological impact[4,9,14–16]. In addition to discomfort and distressing physiological symptoms of pruritus, pain and burning, patients report severe impact on their usual activities of daily living and the avoidance of socialising. Several papers report that poor body image leads to further emotional and psychological symptoms[2–5,9,17].

Research has shown preventative, pre-emptive skin care strategies can mitigate the intensity of skin toxicity in some patients and in turn the impacts on their quality of life and psychological wellbeing[5,16–21]. In 2011 the Multinational Association for Supportive Care in Cancer (MASCC) published evidence-based guidelines for EGFRIs[6]. The guidelines recommend the early implementation of supportive care strategies to delay severe skin toxicity and reduce the need for dose reductions, treatment interruption and discontinuation of treatment[5,19,22]. Evidence-based recommendations for supportive care in preventing and managing EGFRI skin toxicity include patient education at the initiation of EGFRI treatment, including information about frequent moisturising of the skin throughout treatment and avoidance of sun exposure. Health professional education that facilitates an understanding of EGFRI skin toxicity and related skin assessment and documentation is also recommended[1,5–7,11–14].

This evidence implementation project was instigated following a patient report about receiving conflicting advice from members of the multidisciplinary team regarding optimal management of their EGFRI skin toxicity. The patient reported receiving limited education about optimal skin care strategies, despite reporting that her skin toxicity had negatively impacted her quality of life and had increased her distress.

Aim

The aim of the project was to implement evidence-based supportive care for patients with skin toxicity associated with EGFRIs in an ambulatory care setting.

Methods

Design

This evidence implementation project was conducted using a pre/post-audit design. The project was conducted from January 2018 to December 2019.

Setting

The project was undertaken in the ambulatory cancer centre of a large metropolitan hospital in Queensland, Australia. The ambulatory cancer centre has 40 treatment chairs and delivers cancer treatments to around 70–100 adult patients per day. Within this setting approximately 50 patients receive EGFRIs as part of their treatment regimen per year.

Ethical considerations

A submission was made to the hospital Human Research Ethics Committee (HREC) requesting ethical exemption on the basis that the project was directly related to routine patient care and posed no additional risks to standard care. Ethical exemption was granted as well as local governance and privacy office approvals to ensure the project was performed within a safety and quality framework.

Sample

Eligible patients that met the project inclusion criteria were identified from a report generated by the patient integrated management system used in the department. The sample for the baseline audit was all patients receiving EGFRI therapies during the period January – June 2018. The initial report generated 30 patients which included oral and intravenous EGFRI therapies; however, a significant issue was identified in the patient group receiving oral therapy which required separate education and attention, therefore only patients receiving intravenous EGFRI therapies were included (n=16). The sample for the post-implementation audit was patients receiving intravenous EGFRI therapies during the period June – December 2019 (n=13). Some patients were receiving EGFRI therapy for both data collection periods; however, the post-implementation sample excluded patients who were included in the pre-implementation sample as data regarding EGFRI supportive care had previously been collected. The nursing documentation of all identified patients was reviewed using the audit tool developed for the project.

Development of an evidence-based audit tool

The Multinational Association for Supportive Care in Cancer (MASCC) Clinical Guidelines for the prevention and treatment of EGFRI toxicity[6] are evidence-based guidelines identified as the optimal benchmark and standard of care to underpin the project. The MASCC guidelines and supporting evidence were used to develop the audit tool for this project (Table 1).

Data collection

All data for the audit was collected from the patients' healthcare records. Questions 1, 2 and 3 of the audit collected data on whether patients received education and written information about skin toxicity and skin care strategies prior to receiving EGFRI therapy. Questions 4, 5 and 6 collected data on the presence of skin toxicity, use of relevant terminology, and documented skin assessment.

Identifying barriers and strategies to change practice

Findings from the pre-implementation audit informed the identification of barriers preventing the implementation of evidence-based supportive care. The implementation phase included the identification and implementation of strategies to overcome these barriers. The post-implementation audit, using the same criteria as the pre-implementation audit, was carried out to determine the success of the implementation strategies on improving evidence-based supportive care for patients receiving EGFRIs with skin toxicity.

Results

Patient characteristics

The pre-implementation audit included 16 patients; 10 were male and six female with an age range from 34–73 years. The post-implementation audit included 13 patients; eight were male and five female with an age range from 35–78 years. All patients in both the pre- and post-audit data analysis had received intravenous Cetuximab for either metastatic colorectal cancer (n=24) or head and neck squamous cell carcinoma (n=5).

Pre-implementation audit

The pre-implementation audit demonstrated limited compliance with the recommended clinical guidelines, revealing that only 13% (n=2) of patients receiving EGFRI therapies had received specific education and information about skin toxicity and recommended skin care strategies. Skin toxicity was reported in 69% of patients (n=11). For these 11 patients, the use of terminology to describe their skin was poor, with the term 'rash' used consistently in all patient records. Specific EGFRI skin toxicity manifestations were reported in 25% (n=4) of all records where skin toxicity was reported. The generic skin toxicity assessment tool within the hospital's documentation system was completed for 50% (n=8) of the pre-implementation group but documentation failed to provide detail of the type of skin manifestation present.

Implementation phase

Further to a review of the findings of the pre-implementation audit, barriers to implementing evidence-based practice were determined and strategies to improve the implementation of EGFRI supportive care were identified. The lack of education and information provided to patients about skin toxicity and the use of a generic skin assessment tool were considered to be fundamental barriers to evidence implementation.

Implementation strategies were developed and delivered over a period of 12 months comprising two approaches – the delivery of education and training to nursing staff, and the creation and implementation of a specific assessment document to record EGFRI skin toxicity. Education sessions were delivered by a cancer care coordinator who had received education about EGFRI skin toxicity management and principles of oncodermatology. Evidence-based learning materials were used to deliver EGFRI toxicity education to chemotherapy nurses. Four face-to-face small group education sessions were integrated into the existing education schedule in the department, with between four to six nurses attending each session. Six nurses from the department also attended an external comprehensive education event on EGFRI skin toxicity management facilitated by an external drug company that manufactures EGFRI therapy; 14 out of 19 nurses (74%) attended at least one of these events.

The project lead (CK) collaborated with hospital personnel responsible for the patient integrated management system (where nursing documentation is recorded), to create and implement a new and specific EGFRI nursing assessment document within the

Table 1. EGFRI skin toxicity evidence implementation project audit criteria

Audit criteria (pre/post-implementation)	
1	Is there documented evidence that the patient received education about the specific skin toxicity side effects associated with EGFRI treatment?
2	Is there documented evidence that the patient received written information relating to specific skin toxicity side effects associated with EGFRI treatment?
3	Is there documented evidence that the patient received written information outlining the recommended self-care skin care strategies?
4	Is there documented evidence that the patient experienced skin toxicity related to EGFRI?
5	Is there documented evidence of any of the following? ☐ papulopustular / acneiform / follicular rash ☐ hair changes / trichomegally ☐ dry skin / xerosis ☐ paronychia
6	Was the skin toxicity tool completed?

existing system. The MASCC EGFRI Skin Toxicity Tool (MESTT)[23] was used to inform the content for the specific EGFRI nursing documentation.

Post-implementation audit

The post-implementation audit (n=13) demonstrated improved compliance with evidence-based guidelines with an improvement in all audit measures. Figure 1 illustrates the difference in compliance with evidence-based supportive care between the pre- and post-data collection periods.

In the post-implementation audit 85% (n=11) of patients received education regarding EGFRI skin toxicity compared to only 13% (n=2) in the pre-implementation audit. An improvement from the pre-audit was also evident in the provision of written information to patients regarding skin toxicity from 13% (n=2) pre-implementation to 69% (n=9) post-implementation. Similar outcomes were evident in regards to the provision of written directions about skin care strategies. Interestingly, skin toxicity was reported in 100% of patients in the post-implementation audit and had been more accurately described using specific terminology, e.g. 'papulopustular rash' rather than 'rash'.

The newly created EGFRI dermatological nursing assessment had been completed for 92% (n=12) of patients in the post-implementation audit. Although there was a record of skin manifestation in the pre-audit, Figure 2 illustrates the lack of specific terminology documented in the pre-audit compared to use of accurate terminology in the post-audit. Documentation of terminology had improved after the implementation strategies, with all patient records including an appropriate description of the skin manifestation in addition to the use of correct terminology to describe conditions of trichomegally, xerosis and paronychia.

Discussion

The overall project results demonstrate an improvement in the supportive care of patients with skin toxicity associated with EGFRIs. The initial pre-implementation findings support a previous systematic review that suggested that, despite availability of good evidence to prevent and manage EGFRI skin toxicity, the implementation of guidelines frequently failed to reach clinical practice[15].

Cancer nurses routinely deliver patient education about treatment-related side effects and are responsible for ensuring tailored education and information is provided to patients and their families prior to and throughout their treatment and cancer care trajectory[24]. Nurses also play a significant role in the management of skin care, which is regarded as a fundamental element of nursing practice[25], therefore their role in the delivery of supportive care for EGFRI skin toxicity is appropriate and

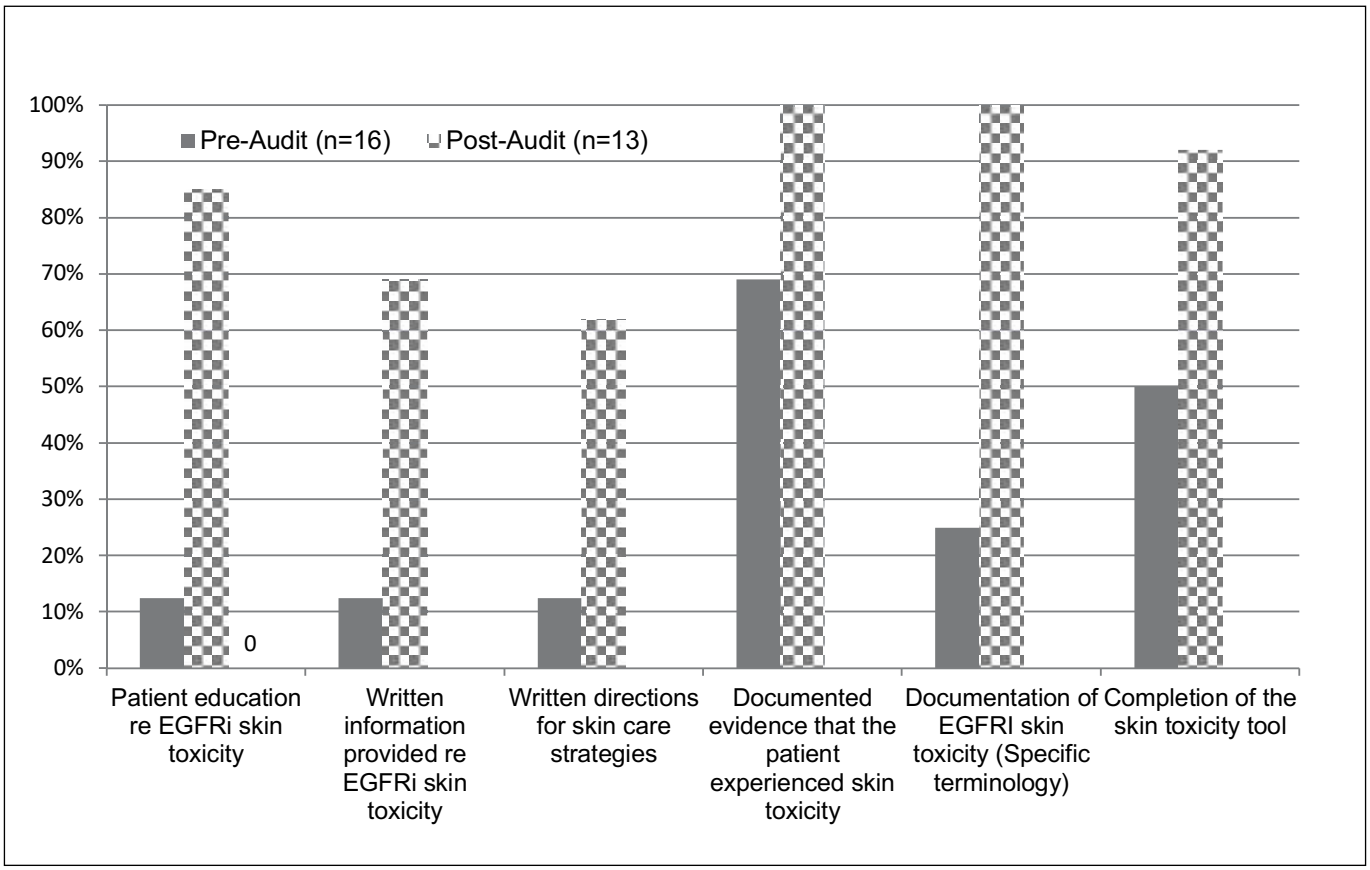

Figure 1. Compliance with evidence-based supportive care for EGFRIs

important. Cancer nurses are well positioned within the team to play a central role in delivering tailored patient education and supportive care to minimise the impact of EGFRI skin toxicity[7,22]; however, nurses may lack confidence in applying evidence-based practice in dermatological care[25]. The results of this project are similar to an implementation project undertaken in China which demonstrated that education of clinicians and patients in regards to EGFRI skin toxicity did not occur routinely and was greatly improved through the implementation of nurse education[11].

Nurse education

Nurses require knowledge about general and specific side effects of cancer treatments if patients are to receive optimal evidence-based care. Cancer nurses are typically not trained in oncodermatology principles, resulting in a lack of knowledge about appropriate skin care, limited dermatological assessment skills, and limited understanding of dermatological terminology[11]. The field of oncodermatology within cancer nursing is an increasingly important area with the growing prevalence of dermatological symptoms in cancer care settings beyond anti-EGFR therapy, particularly with the increased use of immunotherapy[26]. Indeed, in their review of adverse events from immunotherapies and novel therapies, Ciccolini et al.[27] report on the necessity of nurses to be skilled in both dermatological assessment and accurate grading of dermatological adverse events. Their findings reinforce the importance of cancer nurses acquiring and advancing dermatological knowledge and skills in an environment where an increasing number of novel cancer therapies are delivered. Given the increase in the delivery of immune-related therapies which have a dermatological toxicity profile of up to 50%[26,28], cancer nursing education programs should equip nurses to further develop their knowledge and skills in dermatological assessment, related supportive care strategies, and documentation utilising appropriate grading tools.

Nursing documentation and assessment

This project found that the current generic nursing documentation and assessment tool in use was limited in its specificity and capacity to record and monitor EGFRI-specific skin toxicities. Our findings support previous studies which found that the development of specific and focused assessment tools would ensure more accurate monitoring of EGFRI toxicities and implementation and evaluation of related supportive care measures[14,16,29]. Further work was published during the conduct of this project describing the development of a comprehensive skin assessment instrument that extends beyond a single therapy and considers the impact of skin toxicity on quality of life[14].

The lack of appropriate documentation for reporting EGFRI skin toxicity in this setting appears to have led to the frequent use of generic terms. This project highlighted that the use of the term 'rash' in routine nursing practice prevents ongoing accurate assessment of the skin, lacks detail of the type of skin manifestation, and prevents the systematic evaluation of implemented supportive care strategies and treatment. The importance of accurate terminology in monitoring EGFRI toxicity has previously been reported as a crucial factor in optimal evaluation of adverse events and management[29]. Consistency

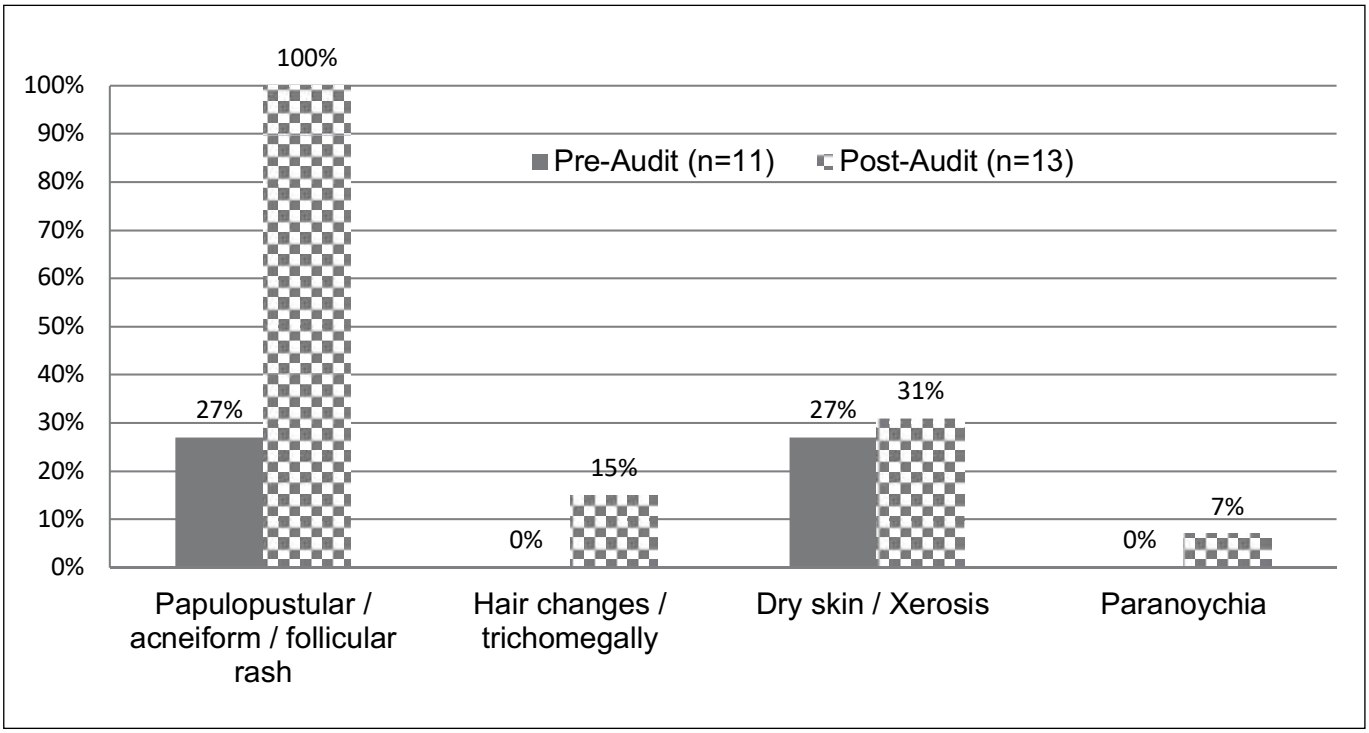

Figure 2. Documented terminology of skin toxicity

in education, evaluation and use of terminology is essential when caring for patients with skin toxicity and supports patient perspectives of being well cared for. Educating nurses on the importance of correct and specific terminology resulted in significant improvements in patient documentation in our context and such education strategies could be implemented in other settings.

A significant limitation of this project was identified during the pre-audit data collection process whereby a consistent and significant gap was noted in the implementation of nursing assessment for all patients receiving oral cancer therapies. Significant disparities between the supportive care of patients receiving oral EGFRIs compared to those receiving intravenous EGFRIs were evident. A decision was made to exclude patients receiving oral EGFRI therapy from this project, with further work to address the needs of this specific group to be undertaken by the clinical department. This finding is an important learning outcome that may be relevant in other settings where disparities in access to supportive care may exist between patients receiving oral and intravenous cancer therapies; acknowledgement of disparities should be addressed to ensure the delivery of high quality evidence-based care for all patients, irrespective of their cancer therapy.

This project demonstrated the importance of listening and responding to the unique patient experience and how this approach can assist health service providers to identify areas of improvement that lead to optimal patient outcomes. In acknowledging the diverse role of the patient in contemporary health services, consideration should be given to accurately monitoring skin toxicity in cancer patients and understanding the real impact on patients and their functional, social, psychological and physical wellbeing[15,21].

Conclusions

Skin toxicity is a significant problem for most patients receiving EGFRI treatments and, although supportive care strategies can reduce the severity and duration of these toxicities, they are not routinely implemented. Patients receiving intravenous EGFRIs require information about skin toxicity and recommended skin care strategies. Cancer nurses are ideally placed to deliver this care but require specific education in dermatological toxicity. Further education and training in the principles of oncodermatology is recommended as a core competency for cancer nurses and especially for those delivering EGFRIs and newly emerging therapies in the ambulatory cancer care setting. Cancer therapy documentation systems and processes should incorporate assessments and grading tools that are specific to the therapies being given to ensure toxicity is closely monitored and appropriate and timely supportive care is delivered.

Conflict of Interest

The authors declare no conflicts of interest.

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PBS Information: Authority required (STREAMLINED). This product is a highly specialised drug listed on the PBS as a Section 100 item. Refer to PBS Schedule for full authority information.

Before prescribing please refer to full Product Information which is available from Ipsen Medical Information. Ph: 1800 317 033 or from http://www.guildlink.com.au/gc/ws/ipsen/pi.cfm?product=ispsatgi

Somatuline® Autogel®: Lanreotide as acetate in a pre-filled syringe (60, 90 and 120 mg). **Indications:** Treatment of acromegaly when circulating growth hormone and IGF-1 levels remain abnormal after surgery and/or radiotherapy or in patients who have failed dopamine agonist therapy; the treatment of symptoms of carcinoid syndrome associated with carcinoid tumours; the treatment of gastroenteropancreatic neuroendocrine tumours (GEP-NETs) in adult patients with unresectable locally advanced or metastatic disease. **Contraindications:** Lactation; hypersensitivity to lanreotide or related peptides or other excipients. **Precautions:** May experience hypoglycaemia or hyperglycaemia (monitor blood glucose levels); slight decrease in thyroid function; may reduce gall bladder motility (recommend gall bladder echography); monitor kidney and liver function; may reduce heart rate in patients without an underlying cardiac problem (monitor heart rate; caution with treatment initiation in patients with bradycardia). Not recommended for use in children. See full PI for further information. **Interactions with Other Medicines:** Reduced absorption of cyclosporin A, decreased bioavailability of cyclosporine, increased availability of bromocriptine, additive bradycardia effects with beta-blockers, decreased clearance of quinidine, terfenadine. **Effect on driving / using machinery:** If affected by dizziness do not drive or use machinery. **Adverse Effects:** Very common: diarrhoea or loose stools, abdominal pain, cholelithiasis; Common: hypoglycaemia, hyperglycaemia, diabetes mellitus aggravated, fatigue, lethargy, asthenia, dizziness, headache, sinus bradycardia, alopecia, hypotrichosis, nausea, vomiting, dyspepsia, flatulence, abdominal distension, abdominal discomfort, constipation, biliary dilatation, steatorrhoea, injection site reactions (pain, mass, induration, nodule, pruritis), laboratory investigation changes, weight decreased, decreased appetite, musculo-skeletal pain, myalgia. See full PI for further information. **Dose:** Acromegaly: For first time treatment the starting dose is 60 mg every 28 days; for patients previously treated with Somatuline LA every 14, 10 or 7 days, the starting dose is 60 mg, 90 mg or 120 mg respectively every 28 days. Dosage should be adjusted according to GH and/or IGF-1 response. Patients well controlled on lanreotide can be treated with 120mg every 42-56 days. Carcinoid Syndrome: 60 to 120 mg every 28 days, adjusted according to symptomatic relief. GEP-NETs: 120mg every 28 days; treatment should be continued for as long as needed for tumour control. **Administration:** Deep subcutaneous injection in the superior external quadrant of the buttock (healthcare professional or carer); or the upper, outer thigh (self-administration). Decision for injection by patient or carer to be made by a healthcare professional. Patients must be controlled on Somatuline Autogel and patients/carers must be motivated, competent and trained to inject. **Storage:** 2-8°C

References: **1**. Martin W et al. Poster presented at 16th Annual ENETS Conference 6-8th March 2019, Barcelona, Spain, Poster H14.
2. Somatuline® Autogel® Approved Product Information March 2019.

For further information about Somatuline® Autogel® contact Ipsen Pty Ltd: T (03) 8544 8100 F (03) 9562 5152 E info@ipsen.com.au Ipsen Pty Ltd, Level 2, Building 4, Brandon Office Park, 540 Springvale Road, Glen Waverley, VIC ,3150 Australia. ABN 47 095 036 909. Somatuline® Autogel® is a registered trade mark. Date of preparation: October 2019 SOM-AU-000595

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