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Editorial

Smoking, stereotyping and stigma: time for a new approach

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Public opinion about smoking has changed drastically since compelling evidence emerged in the 1950s that smoking was associated with the vast majority of lung cancers. Whereas once smoking was an acceptable social behaviour, it is now largely considered to be a deviant behaviour because of its strong association with lung cancer. The unintended consequence of this societal change is that lung cancer patients, in addition to experiencing fear because of their potential for an unpleasant death, also experience significant stigma because of this cancer's associations with smoking[1].

Stigma is an attribute which is socially discrediting, causing an individual not to be accepted as 'normal'[2]. It occurs when society attaches a negative value label to an individual, causing them to feel shame about their condition or situation. Stigma associated with a controllable risk factor, such as smoking, often generates a stronger negative response than non-controllable factors[1]. Lung cancer patients report that their interactions with family, friends and health professionals are often affected, with many patients, particularly those who have given up smoking and or who have never smoked, feeling unjustly blamed for their cancer[1]. The negative impact of smoking-related stigma is exemplified in the following quote from a patient diagnosed with lung cancer who had never smoked:

> *I think all lung cancer patients are stigmatised because of smoking … When I went to see an oncologist for further treatments because I'd had an operation and I'd had half of my left lung removed, I asked them what he thought had caused it and he just laughed and said, "That's obvious, through smoking." And my wife, who was with me at the time, and we've been together since we were 14, she just said, "Well he's never smoked." So, right away what annoyed me as well as that, on my medical records I'm classed as a smoker and every time I ever went for review after that they would ask me, "Are you still smoking?" because that's down there. And no matter how I told them, I'd say, "Look I don't want that on there, I never smoked," it's only my word that can go against that. (LC15, retired joiner, aged 56, recruited through support group)*[1 p.3].

Given the burden of stigma associated with lung cancer, there are growing calls from consumers for clinicians to adopt a new approach to obtaining a complete smoking history. Whilst understanding each patient's smoking history and/or their smoke exposure is critical to managing their care, there is no need for every health professional to ask similar smoking history questions: especially in an era of multidisciplinary care and electronic medical records.

There is a real opportunity for cancer and palliative care nurses to collaborate with lung cancer consumers and to draw upon the expertise of our drug and alcohol mental health and sexual health colleagues to construct an acceptable non-judgemental routine smoking screening and history-taking question set. Taking a comprehensive smoking history once and sharing it with the multidisciplinary team will help reduce the iatrogenic stigma encountered by lung cancer patients, whilst providing opportunities to offer targeted smoking cessation support to those who would benefit most.

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Erratum

In: Opie CA, Koschel A, Ervin KE, Jeffreson L, Haines HM. Supportive Care Screening in Rural Ambulatory Cancer Care. Australian Journal of Cancer Nursing 2017; 18(2) 3-9. On page 5 under the subheading *Characteristics,* the final sentence 'Almost all respondents (96%) had undergone supportive care screening six or more times.' is incorrect and should be deleted. No further discussion in the paper relates to this incorrect sentence.

Cancer Nurses Society of Australia

Algorithm for the prevention, prophylaxis, assessment and management (PPAM) of tumour lysis syndrome

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Abstract

Introduction

Cytotoxic therapies have cell kill capability, capable of initiating an inflammatory condition known as tumour lysis syndrome (TLS), a life-threatening condition that needs to be prevented, quickly assessed and managed for optimal patient outcomes.

Aim

The aim of this literature review was to search the literature and reduce it to levels of evidence between I and VIII and build a TLS algorithm to provide safe and effective care for patients at risk for TLS.

Method

A literature review was conducted between 2 and 23 May 2017. Search terms related to TLS, prevention, prophylaxis, assessment and management were used. A total of 74 articles were retrieved. However, when exclusion criteria were applied, only 23 were finally included.

Results

The literature was critiqued and categorised according to levels of evidence and placed in an algorithm.

Practice implications

Oncology nurses are in an important position to prevent and provide quick assessment and referral for life-saving management of TLS. This algorithm provides a quick reference for TLS protocols of prevention, prophylaxis, assessment and management.

Introduction

The aim of cytotoxic therapies is to kill cancer cells. Cancer therapies are ever-evolving, as is their cytotoxicity on cancer cells. Improved bio and chemotherapies, targeted therapies, bone marrow transplantation, and radiation oncology treatments are improving in their ability to destroy cancers[1]. However, with an improved ability to destroy cancer cells, there is also an increased risk to the patient. When highly proliferative haematological cancers, mediastinal tumours, bulky tumours or chemotherapy-sensitive tumours receive high doses of chemotherapy, rapid cell destruction occurs, and large amounts of intracellular contents are emptied into the systemic circulation, resulting in a condition known as tumour lysis syndrome (TLS)[1-5]. TLS is a complex metabolic disturbance involving abnormally high levels of creatinine, uric acid, potassium, phosphorous and low levels of calcium[1,3,4,6-13].

TLS is a serious condition. It is a rapidly developing medical emergency which may be fatal if unrecognised and left untreated[1-4,6,13-15]. Large-scale release of the intracellular contents of potassium, phosphorous and uric acid lead to clinical manifestations, including cardiac arrhythmias, gastrointestinal disturbance, neurological and neuromuscular abnormalities, and acute renal failure[1]. Acute renal failure may lead to irreversible kidney damage, oedema, liver impairment and the overproduction of cytokines maintaining the inflammatory response, leading to multi-organ damage and death, if unchecked[1,6]. For this reason, identifying TLS and preventing deterioration to life-threatening multi-organ failure is essential.

Background

Presently, cancer therapies are moving more predominantly to outpatient settings. This makes tracking and managing cancer treatment-related adverse events more difficult[5]. For this reason, outpatient centres are important for assessment, cancer treatment, symptom management and multidisciplinary referral for promoting optimal patient outcomes[5]. Cancer survivorship programs are important for improving patient outcomes and integrating collaborative care. The key role for coordinating collaborative care is the oncology survivorship nurse[14]. This highly specialised, ambulatory role is extremely important for assessing TLS risk, preventing TLS and, if needed, referral to an inpatient

setting to mitigate its impact on the patient[16,17]. Consequently, providing optimal care requires a multidisciplinary team, communicating and collaborating together to reduce the risk of TLS[14]. For this reason, the prevention, prophylaxis, assessment and management (PPAM) of TLS demands an easy-to-access tool for risk identification, stratification and management[18]. The ambulatory and the inpatient cancer nurse both play an important role in the PPAM of TLS.

There are four key steps to TLS management. These include prevention, prophylaxis, assessment and management (PPAM)[5,10]. Selected protocols for managing TLS include hyperhydration, allopurinol and rasburicase[5,10,17,18]. However, an initial assessment must take into account patient differences and conditions such as glucose-6-phosphate dehydrogenase (G6PD) deficiency, different types of cancers, kidney function, polypharmacy or nephrotoxic drugs that may influence kidney function and place the patient at differing risk levels for TLS[6,8,13,19]. G6PD deficiency is a condition where the individual is deficient in the enzyme G6PD required to break down rasburicase-generated hydrogen peroxide[27]. G6PD deficiency is a particular problem if rasburicase is used for the management of tumour lysis, and can lead to methemoglobinaemia resulting in haemolytic anaemia, poor organ oxygenation and organ failure[20-22]. Allopurinol used for the reduction of uric acid due to tumour lysis may also be contraindicated with the use of statins, colchicines or drugs causing renal insufficiency[14]. The nurse plays a crucial role in taking a thorough patient history and then documenting this for the prescribing doctor to avoid administration of contraindicated medications. For this reason, the development of an algorithm will enable the nurse to have an easy to access tool for identifying these contraindications and passing this information on to the treating doctor for the management of TLS.

Aims

The aim of the study was to develop an easy-to-use algorithm for the management of TLS for oncology nurses. This is extremely important for busy oncology nurses, who often deal with multiple tasks, doctor's orders, patient symptoms and care[23]. This algorithm will also guarantee up-to-date clinical protocols upon which quick decisions can be made, important to ensure patient safety and efficacious clinical outcomes.

Methodology

A literature search was done of the electronic databases between 2 and 23 May 2017. The search was divided into two stages. The first stage was an exploratory search, which was to examine the broad principles of TLS management. This stage extended from 2 to 4 May 2017. During this stage, CINAHL Complete (EBSCOhost) and Ultimate Search engines were used. Search terms used included 'tumour lysis syndrome', tumour lysis syndrome AND nursing assessment' and 'tumour lysis syndrome AND nursing management'. The second stage of the literature review consisted of developing a deeper understanding of the prophylactic measures and extended from 12 to 23 May 2017. The same databases were used as in stage one, but search terms included 'rasburicase AND tumour lysis syndrome AND management', 'screening AND rasburicase AND tumour lysis syndrome', 'prevention AND tumour lysis syndrome', 'prophylaxis AND tumour lysis syndrome', 'assessment AND tumour lysis syndrome', management AND tumour lysis syndrome', 'age AND tumour lysis syndrome AND assessment', and finally 'assessment AND tumour lysis syndrome'. For both stages, inclusion criteria included full-text, published May 2007 to May 2017, English language, research article and peer reviewed with the Boolean phrase. Exclusion criteria included non-TLS articles and articles with no clear research methodology present.

Results

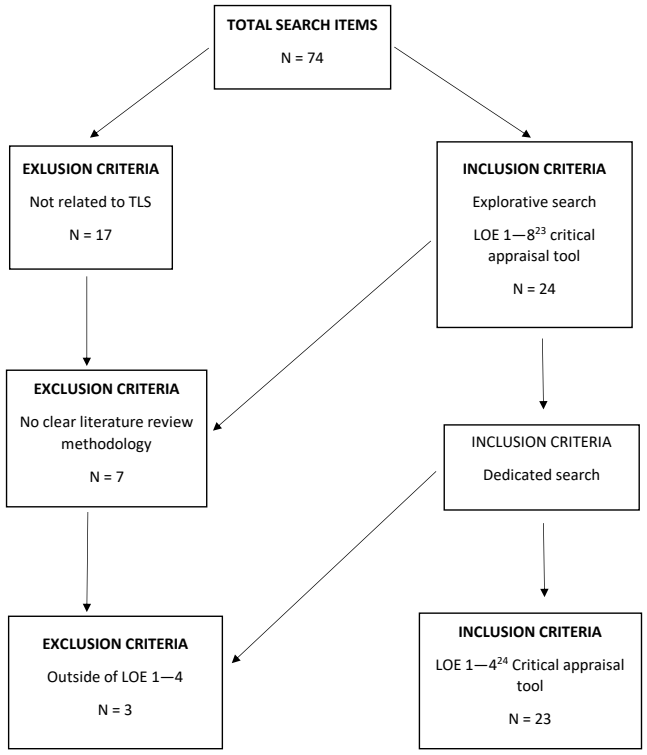
The literature search resulted in 74 journal articles being retrieved. However, all studies that did not meet the inclusion criteria were rejected, resulting in 23 articles being included in the review. The literature was then placed into two different critical appraisal charts. The first was based on the table of evidence adapted from Greenhalgh, Sackett *et al.* and Cochrane cited in Dinsdale, with levels of evidence ranging from V to VIII[24]. Articles with higher levels of evidence, ranging from I to IV were placed in a critical appraisal tool based on Merlin, Western and Tooher's levels of evidence ranging from I to IV[25]. This was done because higher levels of evidence were unavailable for assessment. Additionally, lower levelled literature could be supported by the higher levels when developing the algorithm. This ensured the reliability of the evidence presented (see Table 1 for search results).

Key findings

Prevention

Risk reduction is the first step to preventing TLS. Ambulatory oncology nurses play an important role in risk assessment, categorisation and education to prevent TLS[18,19]. For this reason, Blumel *et al.* state that nurses need to have knowledge of the specific measures required to prevent and manage cancer treatment-related side effects[26]. Cairo *et al.* conducted a literature review and designed a decision tree based on TLS classification and believe that patients should be classified as low, intermediate and high risk based on age, renal function and cancer type[12]. High-risk individuals include those with abnormal electrolyte levels, bulky tumours, highly proliferative haematological cancers, chemotherapy sensitivity, hypertension, congestive heart failure, the elderly, those with renal impairment and patients using pharmaceuticals or nephrotoxins that impair renal function[3,4,11,13,45]. It is imperative that these people are identified before the initiation of chemotherapy or radiation[8]. Intermediate risk patients are those large bulky tumours sensitive to chemotherapy such as neuroblastomas, germ-cell

Table 1: Search results



tumours and small-cell lung cancers[12]. Low-risk patients are those with solid, bulky tumours[12]. The identification of these low-risk patients benefit from reduced laboratory monitoring and prophylactic measures[9].

Patient screening should also be done. Rasburicase is often given as a prophylactic measure for preventing and managing hyperuricaemia, one of the major causes of TLS[27]. However, Africans, African-Americans and those from Mediterranean backgrounds often lack the enzyme G6PD required to excrete bi-products produced by rasburicase, which can result in severe adverse effects such as methemoglobinaemia if rasburicase is administered[14,22]. For this reason, Luzzatto and Seneca suggest that in situations where rasburicase is necessary, G6PD testing should be compulsory. However, they also add the caveat that even when there is a known G6PD deficiency, and when allopurinol is not suitable and the life of the patient is more at risk from TLS than from methaemoglobinaemia, rasburicase may be used with the appropriate management of any sequelae[55].

All the baseline measures, including vital signs, ECG, neurological parameters, electrolytes, including uric acid, potassium, phosphorus and calcium, renal function and hydration should also be assessed[9,10,28,29]. In TLS, laboratory parameters generally change first, after which clinical symptoms including blood pressure, heart rate and rhythm, neurological and neuromuscular symptoms follow[29]. These assessment measures not only form the basis of prevention and management of cancer treatment-related adverse events but also form the basis upon which prophylactic protocols can be based[5,18,19,30]. The ambulatory oncology nurse is in an excellent position to identify individuals for whom particular pharmacological measures might be contraindicated and identify early changes occurring in haematological parameters, documenting this and notifying the treating physician.

Prophylaxis

Once patients have been assessed and stratified for risk, the patient can be referred to the doctor where prophylactic measures can be implemented. The general principles of prophylaxis include increased hydration and observation for low-risk patients, allopurinol, and hydration for intermediate risk and IV hydration and rasburicase for high-risk patients[7,11,12]. The use of prophylactic rasburicase is supported by a number of level I–III-3 studies[31-37]. Cortes *et al.*, in a level II randomised controlled study of 280 patients, and Feng *et al.*, in a level I meta-analysis, both state that rasburicase in doses of 0.05 mg to 0.20 mg/kg/day is more effective than allopurinol at preventing TLS, especially when hyperuricaemia exists[31,32]. Other authors also believe that allopurinol, aggressive hydration and urinary alkalinisation should be initiated two days before the start of cytotoxic therapy[8]. However, alkalinisation is not recommended because it may cause calcium phosphate precipitate in the renal tubules and cause acute renal failure[4,38,39]. Allopurinol is a commonly used uric acid lowering agent in the prevention of TLS, but may cause adverse events in patients taking colchicines or statins and cannot be used to reduce uric acid[4,27,40]. Taking comprehensive and accurate notes of patient medication, noting possible contraindications, and notifying the treating physician are important prophylactic measures. Additionally, nursing education can remind the patient of the importance of adequate hydration.

Assessment

Even with vigorous patient screening and prophylactic measures, ongoing assessment is required for ensuring patient safety and preventing TLS from becoming life-threatening. Oncology nurses play an important role in the assessment of signs and symptoms of TLS and take appropriate action to reduce complications[18]. For this reason, ambulatory and inpatient assessment, and thorough documentation of TLS are essential for oncology nurses. Consequently, they should be familiar with the signs and symptoms of TLS and educate patients in identifying signs and symptoms of TLS[16]. Assessment of TLS can categorised into two types known as laboratory tumour lysis syndrome (LTLS) and clinical tumour lysis syndrome (CTLS). Maloney and Denno state that nurses should be knowledgeable about laboratory values of CTLS, which is characterised by hyperkalaemia, hyperphosphataemia, hyperuricaemia, hypocalcaemia and elevated lactate dehydrogenase, so that early treatment protocols can be initiated[4,19]. LTLS is considered to be present if there are two or more abnormal serum values

of uric acid, phosphate, potassium, calcium, creatinine or lactate dehydrogenase or if they change by more than 25% within three to seven days after treatment initiation[4,8,19,29]. For low to intermediate risk patients, laboratory values, urinary output and fluid balance should be taken every 24 hours, and 12 hours for those at high risk[13,29].

The clinical symptoms follow the abnormal laboratory values. A clinical diagnosis of CTLS is confirmed when there is one clinical symptom and two abnormal laboratory values[11]. Clinical symptoms may present as anorexia, nausea, vomiting, neuromuscular irritability, muscle cramps, seizures, cardiac arrhythmias or arrest, kidney insufficiency, acute renal failure, weight gain, progressive liver impairment or acute respiratory distress syndrome[3,4,6,8]. The prompt identification of these signs and symptoms and initiation of corrective measures are important to avoid fatal outcomes[3,4]. For this reason, in the inpatient setting, ongoing assessment of vital signs, urinary output, weight and skin turgor are important for monitoring patient safety and ensuring optimum treatment outcomes. Howard, Jones and Pui believe that urinary output and fluid balance should be recorded and frequently assessed in those with who are at risk for TLS and high-risk patients should also have continuous cardiac monitoring along with the measurement of electrolytes, creatinine and uric acid every 4 to 6 hours after therapy initiation[29]. Ongoing assessment is important for the management and prevention of adverse events[42].

Management

While prevention deals with preventing the onset of TLS by reducing the formation of uric acid, management is the minimisation of TLS progression into a serious life-threatening condition once LTLS or symptomatic TLS has occurred[51]**.** Once astute nursing assessment have been conducted, management must be quickly implemented. The three major aims of the management of TLS are hydration, renal function preservation and the use of rasburicase, or if the individual has a G6PD deficiency, the use of allopurinol is effective[11,12,19,29,42]. It is important to remember that rasburicase may initiate sensitivity reactions such as rashes, pruritus, methemoglobinaemia, fever, neutropenia, hypoxia and rarely anaphylactic shock[15,18,20]. For this reason, many clinicians have recommended single fixed doses of 5 to 7.5 mg or lower more frequent doses of 0.2 mg/kg IV of rasburicase for high-risk patients, if necessary[12,15,34-37,41-43,46]. Hyperhydration can be done orally, taking 2 litres/m^2 per day or by IV, if required[13,19]. However, in the presence of acute kidney injury (AKI), renal dialysis may be required to clear potassium and uric acid from the system[13].

Patient and carer education

Education is also a major focus of management. The education of patients and their families should focus on how to recognise the signs and symptoms of hyperuricaemia along with the purpose, effects and possible adverse reactions of drugs used for the prevention and management of TLS[53]. Additionally, one of the aims of TLS management is to prevent the formation of calcium-phosphate deposition in the renal tubules exacerbating TLS[54]. Consequently, patients need to be educated to avoid foods that are high in phosphates, such as carbonated drinks, milk or cheese products and foods high in potassium such as bananas, oranges, tomatoes and chocolate[18] (see Table 2 for PPAM algorithm). For this reason, oncology nurses play an important role in TLS management through assessment, knowledge of acceptable drug doses and patient education.

Discussion

The algorithm developed by this author adds an extra dimension to other algorithms. McBride and Westervelt, and Howard *et al.* have included baseline electrolyte measurements, but no basic nursing vital signs, important for the nursing assessment of CTLS, when laboratory values may not be available or have not been done[20,29]. Baseline nursing assessments are imperative, because the nurse is often in more frequent contact with the patient than the doctor, and can, therefore, make more frequent observations. Furthermore, no G6PD deficiency assessment had been included, or possible drug interactions been labelled. Furthermore, Herrington and Dihn have categorised patients into low and high risk, but not included an intermediate risk group, and have also not included baseline vital signs or possible G6PD deficiency[30]. The algorithm that this author has developed includes baseline nursing assessment, low to high-risk categories, G6PD deficiency and nursing care from prevention to management.

Limitations

This literature review has four limitations. Firstly, not all levels of care have levels of evidence of less than IV to support efficacy. The assessment phase of management only had levels of evidence ranging from VI to VII[24]. However, prevention, prophylaxis and management had strong levels of evidence ranging from I to IV[25]. These are areas of critical importance for the clinical management of TLS to ensure efficacious clinical patient outcomes[50]. Secondly, another limitation of this algorithm includes the broad description of TLS management. For greater detail, the reader can refer to other TLS guidelines[39]. Thirdly, other considerations must account for paediatric patients. Finally, it must be noted that these are general guidelines and every case must be taken into consideration on an individual basis. However, this algorithm has given the underlying principles of TLS management, which, if followed, will ensure optimal patient outcomes.

Implications for practice

The ambulatory and inpatient oncology nurse is at the interface between the doctor and clinical outcomes. Laboratory reports can alert to the possibility and risk of TLS. However, the nurse,

Table 2: PPAM algorithm

Prevention		
Baseline laboratory assessments: potassium, phosphorous, uric acid, lactate dehydrogenase, calcium[9,10,28]		
Baseline vital signs: pulse rate and rhythm, respiratory rate, blood pressure, temperature, pain.		
Others: ECG, neurological parameters[10,28,29]		
Education		
Avoid foods high in phosphorus: carbonated drinks, milk, cheese products		
Avoid foods high in potassium: bananas, oranges, tomatoes and chocolate[18]		
Low risk	**Intermediate risk**	**High risk**
Solid bulky tumours[12]	Bulky tumours sensitive to chemotherapy including: Neuroblastomas Gem-cell tumours Small-cell lung cancers[12]	Abnormal electrolyte levels Bulky tumours Highly proliferative haematological cancers Chemotherapy-sensitive cancers Hypertension Congestive heart failure Elderly Nephrotoxins Renal impairment[3,4,11,13,47]
G6PD deficiency[14,22] Concomitant admin of nephrotoxic agents, hypertension[44]		Concomitant use of statins, colchicines[4,27,40]
Prophylaxis		
Low risk	**Intermediate risk**	**High risk**
Alopurinol 100 mg to 300 mg p.o. q8h[12] Vigorous hydration[3] Close monitoring[7]	Hyperhydration 31 m^2 per day[11,12] 100 gm–300 mg allopurinol p.o.qid every 8 hours[12]	Rasburicase single dose of 3–7.5 mg or low doses of 0.2 mg/kg IV over 30 min[3,7,12, 30-34]
Assessment		
Laboratory tumour lysis syndrome (LTLS)	**Clinical tumour lysis syndrome (CTLS)**	
2 or more abnormal laboratory values change by more than 25% within 7 days of treatment Hyperkalaemia Hyperphosphataemia Hyperuricaemia Hypocalcaemia Elevated lactate dehydrogenase[4,8,19] Elevated creatinine[27,52]	2 x abnormal lab values and 1 abnormal clinical symptom. Anorexia, nausea, vomiting, seizures, cardiac arrhythmias or arrest, neuromuscular irritability, muscle cramps, kidney insufficiency, acute renal failure, weight gain, progressive liver impairment and acute respiratory distress syndrome[3,4,6,8,52]	
Low risk and maintenance	**Intermediate risk and prevention**	**High risk and management**
Lab values every 24 hours[13] Urinary output and fluid balance every 24 hours[29]	Lab values every 8–12 hours[13] Urinary output and fluid balance every 24 hours[29]	Lab values every 4–6 hours[29] Continuous cardiac monitoring[29] Urinary output and fluid balance every 24 hours[29]
Low risk and maintenance	**Intermediate risk and prevention**	**High risk and management**
Normal serum creatinine (0.81.4 mg/dL)[48] Uric acid < 10 mg/dL[30] LDH < 500 IU/L[30]	Elevated serum creatinine (≥ 1.5 mg/dL)[30] Uric acid ≥ 10 mg/dL[30] LDH ≥ 500 IU/L[30]	Elevated serum creatinine (≥ 1.5 mg/dL)[29] Uric acid ≥ 10 mg/dL[29] LDH ≥ 500 IU/L[29]
Management		
Rasburicase single fixed dose of 3–7.5 mg or low doses of 0.05–0.20 mg/kg IV[11,12,15,19,30-37,42-46, 49] Hydration and renal function preservation[11,12,19,29,42] 2 Litre m^2 water op or IV/day[13,19] 2500–3000 mL/m^2[29]		
Acute renal failure		
Frequent measurements of potassium every 4–6 hours[29] Renal dialysis[13]		

as the patient's closest clinician, can astutely observe changes in the patient's symptoms and vital signs and then alert the doctor to confirm a diagnosis and take appropriate corrective action. Thus, it is imperative that oncology nurses are aware of the signs, symptoms, contraindications and risk factors of TLS and have an easy-to-use tool upon which to base action.

Conclusion

TLS is a life-threatening condition. Prevention is the best approach. However, due to the nature of cancer and treatment, there are inherent risks. Prevention, prophylaxis, assessment and management lie along the continuum of TLS management. However, astute nursing assessment in the ambulatory setting and management in the inpatient setting lie at the foundation of safe and efficient patient care. For this reason, more research is needed on assessment, so evidence-based risk assessments can be made to reduce TLS risk. Finally, astute and educated oncology nurses with quick and easy-to-use tools are essential to ensure patient safety and efficacious clinical outcomes.

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Examining the feasibility of an online cognitive rehabilitation program in haematology survivorship care to reduce chemotherapy-related cognitive impairment

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Abstract

Purpose

Chemotherapy-related cognitive impairment can adversely impact cancer survivors. This pilot study examines the feasibility of an online cognitive rehabilitation program (CRP) in haematology survivorship care post-autologous stem cell transplantation (ASCT).

Methods

Haematology patients recruited for this multi-site study undertook a nine-week online CRP, commencing day 40± post-ASCT. Patients were evaluated using a neuropsychological tool (CogState) and validated questionnaires at baseline, day 40± post-ASCT, 10 weeks post-CRP and six months post-CRP.

Results

Thirty-two patients were recruited. At interim analysis, 16 patients had completed the CRP intervention. Patients reported high satisfaction and usability with the CRP. At one-week post-CRP completion, patients reported improvements in self-perceived physical well-being and cognitive function. No patient reported clinically significant anxiety or depression scores during the study.

Conclusion

This preliminary data supports the feasibility of an online CRP in survivorship care post-ASCT and full analysis of data is awaited. A future randomised controlled trial is under consideration.

Keywords: Cognitive rehabilitation program, cognitive impairment, chemotherapy, survivorship, haematology and feasibility.

Introduction

Research increasingly indicates that chemotherapy-related cognitive impairment (CI), also known as "chemo brain", is an important adverse effect experienced by many cancer survivors[1-7]. Although typically subtle, emerging results from neuropsychological studies have reported CI in 40–70% of cancer survivors post-chemotherapy[2,8]. This cognitive dysfunction has been shown to persist for up to 10 years[9]. The cognitive domains particularly affected are memory, verbal fluency, attention, concentration and executive function[10-13].

The advancement of cancer therapies and improvement in survival rates means that chemotherapy-related CI has become an area of unmet need and will likely continue to become more prevalent. Chemotherapy-related CI has been shown to adversely impact quality of life (QoL), relationships, employment and activities of daily living (ADLs)[2,7,13-16]. It can pose significant problems for patients as they attempt to resume their lives following treatment[15]. Existing literature is limited in terms of aetiology, effective prevention and therapy. Proposed underlying pathogenesis has included cytokine release, cerebrovascular

injury, fatigue, inflammation, autoimmune responses and direct chemotherapy-related neurotoxicity[13,17].

Haematopoietic stem cell transplantation (SCT) is an essential therapy for many haematological malignancies. An SCT is preceded by high-dose conditioning chemotherapy, and patients are at risk of developing CI and delayed encephalopathies[4,18-21]. Autologous stem cell transplantation (ASCT) is a type of SCT that involves harvesting of the patients' own stem cells, with subsequent reinfusion back into the patients post high-dose chemotherapy. The procedure has been used for patients with various haematological disorders, including myeloma, lymphoma and amyloidosis. CI following ASCT is emerging as a widespread and significant concern for these patients[19,22]. A recent study, involving multiple myeloma patients, performed neuropsychological tests before and after ASCT and reported that 49% of patients demonstrated a clinically significant cognitive decline one month post-ASCT[19]. Another recent cross-sectional, descriptive study exploring the needs of haematological patients post-SCT reported that coping with a "bad memory or lack of focus" was the highest unmet need of ASCT survivors[22].

Despite the reporting of CI post-ASCT in the literature, no specific rectification strategy is currently in routine practice.

Cognitive rehabilitation programs (CRPs) aim to improve or restore cognitive function and have the potential to increase QoL for those with chemotherapy-related CI[23-26]. A number of studies have examined CRPs as a potential tool to enhance the cognitive abilities of patients, including cancer survivors post chemotherapy, with encouraging results[27-31]. Several studies have also reported improvements in psychological, physical and social functions[24,26,31]. A recent randomised controlled trial (RCT) evaluated the efficacy of an online CRP in cancer survivors. The study reported a significant improvement in perceived CI in the CRP group, compared to the non-CRP group. There were also significantly lower levels of anxiety, depression and fatigue favouring the CRP intervention[31].

Computer-based CRPs tend to involve repeated skill practice, dynamic difficulty adjustment, and an engaging and satisfying environment[32,33]. The advantages of an online CRP include: (1) accessibility at patients' preferred time and place; (2) anonymity; (3) affordability; (4) self-empowering and capacity building; (5) self-determined flexibility; and (6) rewarding (immediate feedback regarding progress)[32-34].

Context of the study

In 2014 the lead site for the study, a major Victorian tertiary referral hospital, commenced a weekly haematology nurse-led survivorship clinic to provide further holistic care for patients post-treatment completion. An audit of the first 50 patients was performed[35]. All the patients had received chemotherapy, the median time post-treatment completion was four months and nearly half (42%) were post-ASCT. The findings of the audit resonated with the international literature, highlighting the prevalence of chemotherapy-related CI and the associated adverse impact on QoL and ADLs. Almost half of the patients (47%) reported memory/concentration problems, and of these patients, half (50%) had previously had an ASCT. Moreover, 40% of patients reported coping with memory/concentration problems as a moderate to very high unmet need in the past month prior to attending the clinic[35].

Study goal and endpoints

The overall goal of the study was to enhance the post-ASCT cognitive recovery of patients treated for a haematological malignancy that will then translate into improved psychological, physical and social functions.

Primary endpoints

1. To evaluate the feasibility of introducing an online CRP into routine clinical follow-up care.
2. To evaluate the prevalence of CI post-ASCT and the related effects on the patients' QoL.
3. To analyse the extent of CI pre-ASCT secondary to previously received chemotherapy.

Secondary endpoint

4. To assess the efficacy of an online CRP in either reducing the degree of or accelerating the recovery of CI in this cohort.

As this is not an RCT, a definitive conclusion about efficacy is not possible.

Methodology

Study design

This was a multi-site, collaborative pilot study, with the lead site a major Victorian tertiary referral hospital. The other participating sites included a major metropolitan and major rural public hospital. Figure 1 summarises the routine clinical care (red boxes), the study procedure (blue boxes) and the study assessment time points (green boxes).

All the potential ASCT patients from the participating hospitals who had a planned stem cell harvest at the lead site were considered for the study.

When an appropriate patient attended their routine apheresis clinic appointment, the study was presented and discussed. Patients who were interested were provided a patient information and consent form (PICF). The patients who were willing to participate signed the consent as per good clinical practice (GCP) guidelines.

A baseline cognitive assessment was performed prior to the ASCT (T1). A post-ASCT cognitive assessment was performed on

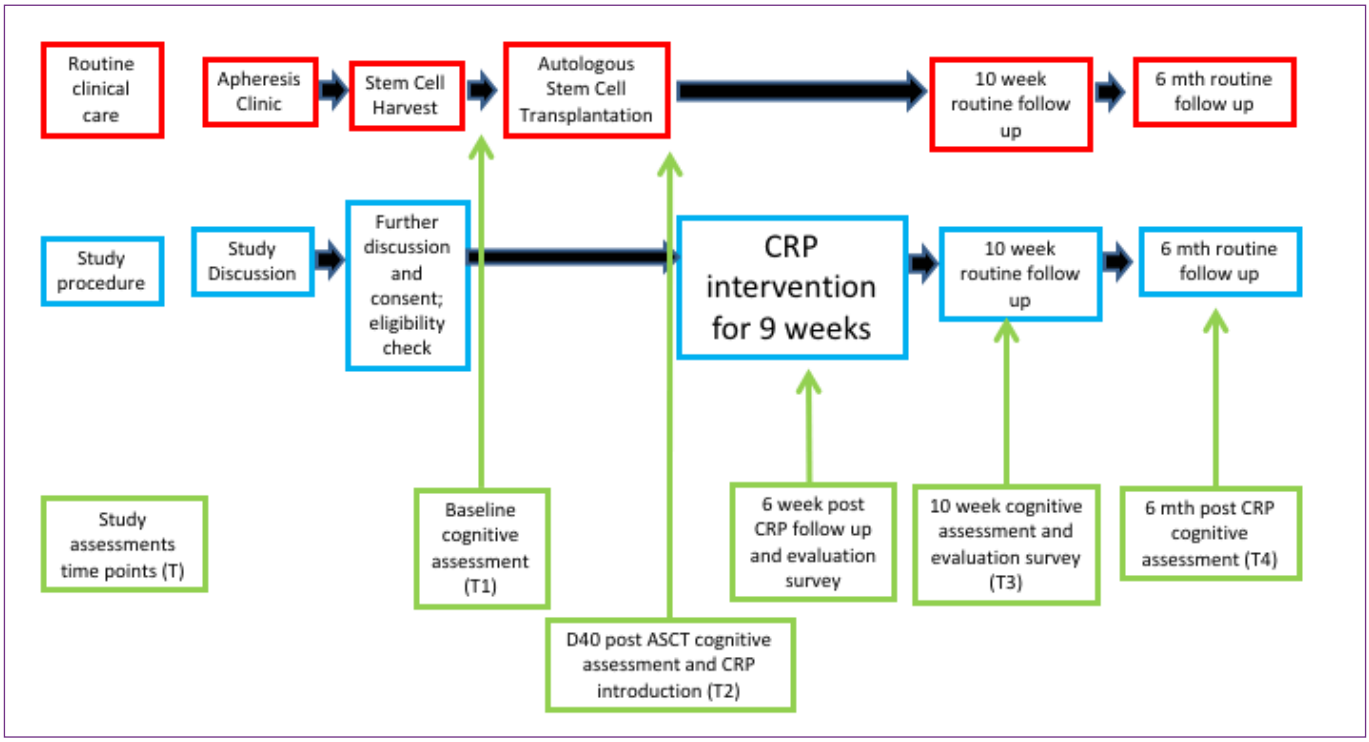

Figure 1: Study schema

day 40± from the ASCT (T2). At this assessment, patients were introduced to the online CRP. Patients were asked to use the CRP for 120 minutes per week for nine consecutive weeks.

An evaluation survey was completed at six weeks and at the completion of the CRP to determine the patients' perceptions of the efficacy and usability of the CRP, as well as their satisfaction with the program.

One week post completion of the CRP intervention, a third cognitive assessment was performed (T3). A final cognitive assessment occurred at six months to determine the longevity of effects observed (T4). Routine survivorship management continued, regardless of whether the patients were in the study or not. Table 1 lists the eligibility criteria for the study.

Data collection and measures

Both qualitative and quantitative data were collected and analysed in this study. Demographic data were recorded from the patients' medical records and a questionnaire completed at baseline.

Table 1: Study eligibly criteria

Inclusion criteria
Aged ≥18 years of age
From a participating institution with a haematologic malignancy requiring an ASCT
Able to read, comprehend and follow the English instructions of the CRP
ECOG performance status ≤2
Adequate computer and internet access, and basic IT competency to perform the CRP
Exclusion criteria
Prior or planned cranial radiotherapy
Uncontrolled psychiatric, psychological, neurologic or medical conditions that may compromise compliance or lead to prolonged hospitalisation
Use of psychoactive medications known to affect cognitive functioning
History of or current substance abuse
Concurrent poorly controlled depression or anxiety
Abbreviations: ASCT, autologous stem cell transplantation; CRP, cognitive rehabilitation programs; ECOG, Eastern Cooperative Oncology Group; IT, information technology

At each of the four cognitive assessments, patients were evaluated using CogState, a computerised neuropsychological tool. CogState measures objective cognitive function, including memory, attention and executive function[36-38]. Patients also completed questionnaires assessing subjective cognitive function, anxiety and depression, QoL and stress.

The questionnaires used in this study were:

1. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire — Cognitive Functioning subscale (EORTC QLQ-CF).
2. Functional Assessment of Cancer Therapy — Cognition subscale (FACT-COG).
3. Functional Assessment of Cancer Therapy — Bone Marrow Transplant subscale (FACT-BMT).
4. Hospital Anxiety and Depression Scale (HADS).
5. The Perceived Stress Scale — 14 items (PSS-14).

The EORTC QLQ-CF is a validated tool in cancer patients that measures subjective cognitive function[39]. FACT-COG was designed to assess cancer patients' perceived cognitive deterioration[40,41].

Given that emotional well-being and fatigue are thought to be contributors and confounders to cognitive dysfunction, the FACT-BMT[42], the HADS[43], and the PSS-14[44] were utilised to assess these factors.

A 25-item evaluation survey was developed to assess patients' experience with the CRP intervention. It contained seven sections: ease of learning; perceived efficacy; usability; satisfaction; compliance; predicted future use; and the World Health Organization 5-item Well-Being Index (WHO-5)[45].

Feedback about the CRP was also collected weekly throughout the nine-week intervention period.

The intervention

The CRP for this study was *BrainHQ* from Posit Science. It is an internet accessible program designed to enhance multiple cognitive functions[46,47]. *BrainHQ* targets visual and auditory processing systems aiming to improve cognition by augmenting information processing[47,48]. The *BrainHQ* exercises have elements of a computer game and incorporate skills often thought of as innate, such as deciphering key sounds from background noise and comprehending fast or mumbled speech. *BrainHQ* is the most recent version of the Posit Science CRPs *Brain Fitness* and *InSight*, which have reported success in cancer populations[26,31].

Ethics

Full high-risk ethics approval was obtained in September 2016 from the Human Research Ethics Committee (HREC) of the lead site (HREC Reference Number: HREC/16/Austin/226). This HREC operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans (2007), the Note for Guidance on GCP, the Health Privacy Principles described in the *Health Records Act 2001* (Vic) and Section 95A of the *Privacy Act 1988*.

Updated study protocols and PICFs were communicated to this HREC appropriately.

Each patient enrolled in the study was de-identified and assigned a study number. All authors had access to study data and all investigators ensured patient confidentiality and safe record keeping.

Data analysis

Descriptive statistics of mean values, standard deviation (SD) and range were used to analyse continuous variables; categorical data was calculated in numbers and percentages.

CogState scores less than 1SD of the normative population mean were considered impaired scores, and a change of +/–1.5SD was considered a meaningful improvement/decline[49].

Patient-reported outcome (PRO) scores for QoL, cognitive function and stress were analysed as group means. Where available, cut-off scores were determined using published reference values[40,50-53]; otherwise, poorer function was determined as +/–1SD of the population mean, and meaningful change was 10% of the score range. The HADS is a clinical diagnostic instrument, therefore individual scores were analysed. A score of ≥11 was considered clinically significant depression and/or anxiety[54].

This was an interim analysis with a small sample size, a formal statistical analysis is planned for 2018.

Results

Between November 2016 and July 2017, 60 patients were assessed for study eligibility. Of these, 47 (78%) patients were eligible. Reasons for ineligibility included: 1) unable to follow the English instructions of the CRP; 2) ASCT not within study time frame; 3) inadequate computer or internet access; and/or 4) information technology (IT) incompetent. Thirty-two patients consented to the study; the recruitment rate was 68%. Reasons for decline included: 1) unwilling to travel to lead site for cognitive assessments (n=5, 33%); 2) not interested in cognitive rehabilitation (n=5, 33%); and/or 3) lack of time to complete the CRP intervention (n=4, 27%). Participant eligibility and recruitment is outlined in Figure 2.

This interim analysis was undertaken in August 2017 and included 16 patients who had completed only the first three of four study time points (baseline, day 40+/–5 post-ASCT and one week post-CRP completion). The demographic and clinical characteristics of the study participants are presented in Table 2. The mean age was 58 years (SD=10.7); 10 (63%) were male and

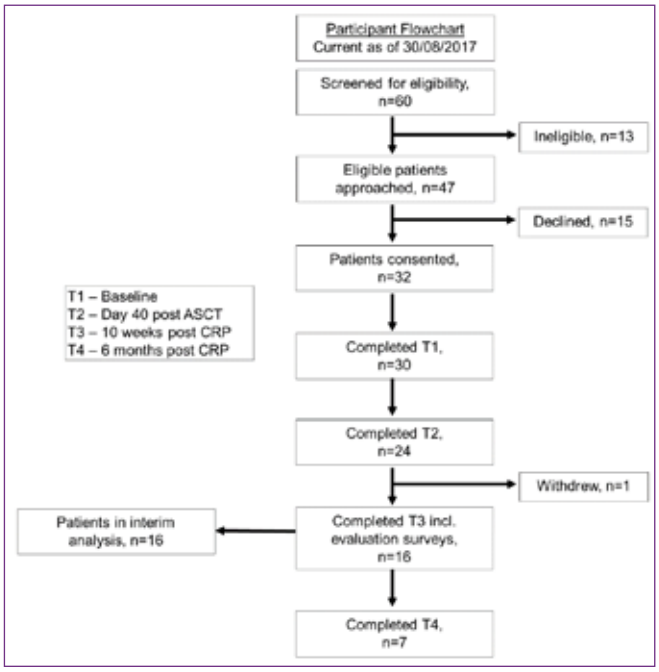

Figure 2: Participant flowchart

10 (63%) had multiple myeloma. All patients had previously completed chemotherapy and the mean time since diagnosis was 3.4 years (SD=4.3).

Of the 16 patients who have completed the intervention period, 15 (94%) used the CRP. The average total training time was 910 minutes (60 to 1833 minutes) of a recommended 1080 minutes. Seven (44%) patients completed the recommended CRP prescription in the nine-week time frame. Reasons for CRP non-compliance included a combination of: 1) Illness/disease progression and/or subsequent hospital admissions (n=5, 56%); 2) competing priorities (n=4, 44%); 3) internet access or computer issues (n=2, 22%); and 4) vacations (n=2, 22%).

The CRP evaluation survey data highlighted that patients were satisfied with the intervention, found it easy to use and felt it improved their cognitive functions (Table 3). This is in line with qualitative CRP evaluation data that strongly reflected a positive experience with the program. Patient comments included: *"It gives me purpose and puts a bit of structure back into my life. I enjoy sitting down at a laptop and doing something that is good for me""* (ID 4) and *"I found the program so beneficial overall. It helped my brain deal better with multitasking and concentration"* (ID 8). The survey asked patients if they would have preferred a different mode of cognitive rehabilitation, for example, in-person workshops or puzzle workbooks; 88% reported that they were satisfied with the online, computer format; *"I liked that I could choose when I did the training, and I didn't need to leave the house or make an appointment"* (ID 2).

Table 2: Baseline demographic and clinical characteristics (n=16)

Characteristics	n=16	%
Sex		
Male	10	62.5%
Female	6	37.5%
Age, years		
Mean (SD)	58.2 (10.7)	
Range	28–70	
Diagnosis		
Multiple myeloma	10	62.5%
Non-Hodgkin lymphoma	3	18.8%
Hodgkin lymphoma	2	12.5%
Amyloidosis	1	6.3%
Time since diagnosis, years		
Mean (SD)	3.4 (4.3)	
Range	0.4–15.1	
Conditioning regimen		
Melphalan 200 mg/m^2	8	50.0%
Melphalan 140 mg/m^2	3	18.8%
BEAM	5	31.3%
Cancer treatment modality		
Chemotherapy	16	100.0%
Chemotherapy and radiotherapy	5	31.3%
ECOG performance status		
0	10	62.5%
1	6	37.5%
Educational attainment		
Year 10	3	18.8%
Year 12	3	18.8%
Diploma	2	12.5%
Associate's degrees	2	12.5%
Bachelor's degrees	5	31.3%
Master's degrees	0	0.0%
Doctoral degree	1	6.3%
Employment status		
Employed (working >30 hr)	1	6.3%
Employed (working 10–30 hr)	4	25.0%
Employed (working <10)	4	25.0%
Employed (leave)	0	0.0%
Retired/pensioner	1	6.3%
Not employed	6	37.5%
English as first language		
Yes	14	87.5%
No	2	12.5%

Abbreviations: SD: standard deviation; BEAM: BCNU, etoposide, cytarabine, melphalan; ECOG: Eastern Cooperative Oncology Group.

Table 3: CRP Evaluation Survey results, score range 1–5 (n=16)

CRP Evaluation Survey	6-week data (during CRP) Mean (SD)	10-week data (post-CRP) Mean (SD)
Easy to learn	4.5 (0.4)	4.6 (0.4)
Efficacious	4.0 (0.5)	4.0 (0.8)
Easy to use	4.5 (0.5)	4.6 (0.5)
Satisfied	4.4 (0.4)	4.4 (0.7)

Mean (SD). Five-point Likert scale; "1 Strongly disagree" to "5 Strongly agree".

CRP; Cognitive rehabilitation program

At T3, one week post-CRP completion, there was a meaningful change, corresponding to an increase in function, in the FACT-BMT subscales for physical well-being (PWB), functional well-being (FWB) and Trial Outcome Index (TOI) (Table 4). The TOI incorporates the scores of the PWB, FWB and Bone Marrow Transplant subscales.

Despite efficacy not being a primary endpoint, there was also a meaningful change, corresponding to an increase in perceived cognitive function, in the EORTC QLQ-CF post-CRP (Table 5).

The mean PRO scores post-ASCT (T2) were lower than baseline (T1) but did not reach a meaningful change level (Table 4). So far, objective cognitive function, measured by CogState, did not demonstrate a meaningful change however, given that this is only an interim analysis, final complete data will need to be awaited.

Similarly, as determined by the HADS, no patients reported scores indicating clinically significant levels of depression or anxiety and final results are awaited.

Discussion

Chemotherapy-related CI is a well-recognised problem that is expected to become more prevalent and previous studies have heavily focused on breast cancer patients[6,7,15]. Further research in other cancer groups is required to better understand the nature and magnitude of this cognitive dysfunction.

Table 4: Patient-reported outcomes mean analysis (n=16)

Questionnaires	T1. Baseline Mean (SD)	T2. Post-ASCT Mean (SD)	T3. Post-CRP Mean (SD)	Change (T1–T2)	Change (T2–T3)	Meaningful Change
Perceived Stress Scale Score range: 0 to 40	11.0 (4.1)	11.2 (5.7)	9.1 (5.1)	0.2	−2.1	4.0
EORTC QLQ-CF Score range: 0 to 100	83.3 (17.2)	77.1 (20.1)	87.5 (15.5)	−6.3	10.4	9.0
FACT-BMT Physical Well-Being Score range: 0 to 28	21.6 (3.4)	19.6 (4.4)	22.6 (4.3)	−2.0	3.0	2.8
FACT-BMT Social Well-Being Score range: 0 to 28	23.9 (3.1)	23.7 (2.9)	24.2 (3.2)	−0.3	0.5	2.8
FACT-BMT Emotional Well-Being Score range: 0 to 24	19.7 (3.0)	19.6 (3.2)	20.3 (3.3)	−0.1	0.7	2.4
FACT-BMT Functional Well-Being Score range: 0 to 28	19.6 (4.7)	17.6 (5.1)	21.1 (6.0)	−1.9	3.5	2.8
FACT-BMT TOI Score range: 0 to 96	69.9 (11.4)	63.9 (13.6)	74.0 (12.9)	−5.9	10.1	9.6
FACT-BMT Total Score Score range: 0 to 148	113.5 (14.3)	108.2 (17.7)	118.5 (17.1)	−5.3	10.3	14.8
FACT-COG Total Score Score range: 0 to 132	108.2 (19.4)	104.2 (21.8)	110.4 (18.7)	−4.0	6.2	13.2

EORTC QLQ-CF and FACT questionnaires — higher scores indicate better well-being
Perceived Stress Scale questionnaire — higher scores indicate more perceived stress

This pilot study was conducted to determine the feasibility of an online CRP to reduce chemotherapy-related CI post-ASCT for treatment of a haematological malignancy. The study was not designed to conclusively validate the efficacy of the CRP in reducing post-ASCT cognitive dysfunction. As such, although observations regarding the efficacy of the CRP could be made, a key limitation was that this study was not powered to detect actual effectiveness of the intervention. Furthermore, given that this is an early interim analysis, completed data is needed to consolidate the findings so far.

Regarding feasibility, patients engaged in the CRP enthusiastically and the nine-week intervention was well received. The vast majority of patients reported high intervention satisfaction, found the program easy to use and felt it was beneficial for both their cognitive functions and overall health. Non-compliance with the CRP intervention was largely due to illness and/or disease progression, often accompanied by hospital admissions.

The inclusion of cognitive rehabilitation in ASCT follow-up care provided patients with the opportunity to discuss their cognitive concerns, an area reported by this cohort as an unmet need[22,35]. The online format of the CRP enabled patients access to a validated health tool without an increase in hospital contact hours. Furthermore, the self-directed nature of the program encouraged active participation by the patients in their own health management, promoting self-capacity building[33].

The interim analysis demonstrated that, at one week post-CRP completion, patients reported improvements in physical and functional well-being and self-perceived CI. These positive results are in line with recent literature[23,26,31], and provide support for the use of online CRP as a sustainable model of care post-ASCT. However, as this was a single-arm pilot study, a definitive conclusion regarding CRP efficacy could not be confirmed. Any perceived benefit from the CRP should be considered in the context of the natural healing process by the patients themselves post-ASCT. It is hoped that the information gathered from this study will lead onto an RCT designed to examine the efficacy of the CRP intervention.

There were limitations to this study, one of which was the small sample size. Another limitation was that all eligible patients were high functioning (ECOG ≤2), spoke English and were computer literate. The patient sample was primarily Caucasian and highly educated, with half the sample holding a tertiary degree. Patients with less education, non-English-speaking and/or unfamiliar with computer technology may struggle or be unable to complete the online CRP.

The mean PRO scores for cognitive functioning did not seem to demonstrate a meaningful decline post-ASCT. There are several plausible explanations for these unexpected findings. e.g. The mean PRO scores for cognitive functioning did not seem to demonstrate a meaningful decline post-ASCT. There are several plausible explanations for these unexpected findings. It may be due to the different measures or timeline used to assess cognitive dysfunction. For example, in this study, patients were assessed day 40± post-ASCT; in the study by Hahn *et al.*[22] the assessment was conducted 1–5 years post-SCT. The contrary findings demonstrate the difficulty in pin-pointing the exact timing of CI post ASCT and this is an area where future research is warranted. Other possible explanations for the different findings include the small sample size of the interim analysis, and the inclusion of patients irrespective of baseline cognitive function. All patients had previously received chemotherapy and, as demonstrated by the EORTC QLQ-CF, many patients reported experiencing cognitive complaints at the baseline assessment. The attempt to include all patients, even those with subtle CI, may have reduced the study's capability to detect cognitive decline post-ASCT. Future research would benefit from approaching treatment-naïve patients.

In conclusion, this interim analysis supports the feasibility of an online CRP in haematology survivorship care post-ASCT. A final statistical analysis will be conducted once all the patients have completed the CRP intervention. These results aid in the design of a future RCT specifically examining the efficacy of the online CRP. This study highlights the implications for nursing practice, as it emphasises that chemotherapy-related CI is a recognised problem and that further research is required to better understand the nature and magnitude of this cognitive dysfunction.

Although more research is warranted, this represents a positive step forward in addressing the need for interventions targeting chemotherapy-related CI for cancer survivors.

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Cancer Nurses Society of Australia

Living on: an exploration of healthful cancer survivorship among grey nomads

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Abstract

Aim: To explore the experiences of grey nomads living with a diagnosis of cancer.

Background: Cancer is primarily both a life-limiting and a chronic condition of ageing and older people. Older people, however, are not a homogeneous group; there are several generations and many different groups to be considered. Grey nomads are one such group and are characterised as being retired and travelling domestically for extended periods of time, usually in a caravan or motorhome.

Design: Prospective qualitative phase of a larger, sequential, explanatory, mixed-methods project.

Methods: A series of 14 semi-structured, in-depth interviews were conducted over six months in 2016 with 14 self-identified grey nomads living with a diagnosis of cancer. Interviews were analysed using thematic analysis.

Results/Findings: Participants travelled despite of, and because of, their cancer diagnosis. These two key themes, with their associated sub-themes, explain how older people incorporated their cancer-related work, that is to say, managing their cancer-related follow-up and treatment health needs into their travelling life; how they normalised it; and how they developed strategies for healthful survivorship.

Conclusion: Participants were living healthfully in that they were living a lifestyle that promoted their well-being. Participants developed strategies in response to their changed environment and thus created new capacity to support what they wanted to do. Despite being cancer survivors — some of whom were undergoing active treatment — participants gained 'healthfulness' through their chosen nomadic lifestyle.

Introduction

An increasing number of older Australians, colloquially known as 'grey nomads', take to the road on retirement. In 2011, Australia's grey nomad population was estimated to be about 2% of the total population (or about 450,000 people)[1]. The seasonal nature of the grey nomad lifestyle provides challenges for both receiving and delivering health care to support cancer survivorship[2]. There is a dearth of literature focusing on the health and health needs, cancer-related or otherwise, of grey nomads[3,4].

Background

Cancer diagnoses in Australia increased almost twofold between 1991 and 2012[5]. This is a trend that is largely explained by both an increasing and an ageing population. Concurrent with the rising incidence of cancer diagnosis is a decreasing associated mortality. This is largely due to improved cancer screening, early diagnosis, together with improved and targeted treatments. Five-year survival overall has improved from 47% in 1982–7 to 66% in 2006–10[5]. As well as being a malignant disease, cancer is a personal experience that affects individuals in far-reaching ways.

For people living on after their diagnosis, cancer is an intimate and integral part of everyday experience, so it is a social and personal issue in addition to a medical problem. Cancer survivorship has been characterised as living on after a cancer diagnosis[6,7], and as a life-changing experience[8-15], with both positive and negative aspects[6]. There is little consensus in the

survivorship literature, however, as to who is a cancer survivor and when they become one[6,11,12,14,16-18]. For the purposes of this paper, cancer survivors are defined as those people who self-reported a cancer diagnosis in the online survey that formed the first phase of this project.

Frank[19] suggests that a survivor is someone who has overcome an adversarial event, and that the process of survivorship is a "craft activity" (p. 251). This he characterises as an embodied skill of surviving. Whilst the science of survival seeks to understand the disease, the craft of survival seeks to understand the human experience of the disease[20, p.1475] or as Stephens[21] puts it "living on". Therefore, this study may be characterised as a study of one activity in the craft of cancer survivorship. As with survivorship, health too is "grounded in the experiences and concerns of everyday life ... [and it] provides a means for personal and social evaluation"[22, p.62].

Health has been conceptualised as being experienced when an individual has the capacity to support their goals, projects and aspirations[23] and as being functional[24]. McWilliam, Stewart *et al.*[25, p.7] illustrated this empirically in their study of older people and their ideas about health. Health, they said, is "being able to do what you want to do" (p. 7) as well as feeling in harmony with the environment, thus being able to carry out everyday activities within one's own environment. Healthful living is a term that has been used in the literature since 1915 to describe a way of living that is conducive to good health. Further, healthfulness[26] — a concept that has been used variously over several centuries to describe conditions for health and wellness among populations and, more specifically, with regard to nutrition — has been developed more recently by Seedhouse[27,28] in his conceptualisation of the foundations theory of health to describe the conditions required for health. Seedhouse[27] argues that autonomy is a central component of health and further suggests that respecting autonomy is more important than creating autonomy[27]. If health is the foundation for achievement[28], healthfulness creates the conditions for achievement and, thus, health.

Given the numbers and the potential vulnerability, older cancer survivors have become an especially important group to study. However, older people are not a homogeneous group. There are several generations and many different groups to be considered; for example grey nomads, specifically with their chosen lifestyle. Literature that has explored grey nomadism has largely focussed on the economic impacts of grey nomad tourism[4,29,30] and the impact of their seasonal travel on existing health services[4]. There are no reports specifically looking at grey nomads living on with a cancer diagnosis. Therefore, we need to understand more about their experiences and health needs to help generate a research agenda with this group of older people.

The study

Aim

To explore the experiences, health needs and strategies of grey nomads living on after a cancer diagnosis.

Method

Study design and participant recruitment

This paper reports on the qualitative component of a larger, sequential, explanatory, mixed-methods project exploring the health, health needs and experience of grey nomads. Specifically, this component explored the experiences of grey nomads living with a cancer diagnosis. The first phase comprised an online survey of individuals who had travelled around Australia for more than three months, during the previous 12 months. Survey data has been reported elsewhere[3]. Survey respondents provided their consent and contact details if they were willing to participate in the subsequent interviews. Of those who consented for an interview, individuals were purposively selected if they had reported a cancer diagnosis. Participant recruitment continued until data saturation was achieved, in other words, when emergent themes became recurrent and no new themes or patterns were uncovered[31].

All interviews were undertaken by telephone, due to the geographical location of participants, by one researcher during April/May 2016. Semi-structured interview questions focussed on health needs, planning, well-being and experience while travelling, specifically focussed in relation to their cancer diagnosis. In addition, prompts were used to encourage participants to explore their experiences in more depth. Interviews were audio-recorded and transcribed verbatim by a professional transcription company. Inductive thematic analysis was used to analyse the data, using the Braun and Clarke[32] framework. Firstly, ideas and pre-understandings of the research team were noted prior to data collection consistent with a reflexive approach, which enhanced the trustworthiness and transparency of the research. Then, a second researcher familiarised themselves with the data; generated initial codes; searched for themes; reviewed, named and defined themes; and crafted the report[32]. Validity, or trustworthiness, pertains to the credibility, believability and faithful interpretation of participants' experiences[33]. In this study, trustworthiness was established through the purposive selection of participants and qualitative approach used to explore the experiences of grey nomads living with a cancer diagnosis. Recordings were repeatedly listened to by the researcher undertaking the data analysis and the verbatim transcripts themed using NVivo software to manage coding.

Ethical considerations

Approval for this study was gained from the Human Research Ethics Committees of the University of Wollongong (Ethics Approval Number: HE15/366). Written consent was collected

from each participant prior to the interviews. Pseudonyms have been used to preserve confidentiality.

Findings

Of the 316 respondents completing the online survey, 18 individuals identified as having a cancer diagnosis and consented to be contacted for an interview. Data saturation was achieved after 14 in-depth interviews. The duration of most recent travel for these participants ranged from four months to 15 years. Interviews lasted between 28 and 42 minutes.

Participants talked about travelling — where they defined travel as being on the road or living in a caravan/motorhome away from home — in two key ways: despite of; and because of, their cancer diagnosis. These two key themes which were further categorised into sub-themes. These explained how older people incorporated their cancer-related work — the activities that they undertook to manage cancer treatment and follow-up — and the challenges into their ongoing travelling life and how they developed strategies for healthful survivorship.

Travelling despite a cancer diagnosis

Cancer was not a barrier to travel for the majority of participants because they integrated organising their treatment, follow-up and management of treatment sequelae into their everyday lives. Participants described how they undertook organisational/planning tasks to maintain their continuity of care and described their specific strategies for effective planning. The two key areas that required planning expertise were: organising and managing cancer treatment on the road; and organising follow-up or other health screening. Both of these demands required participants to seek out supplies and services, adapt route planning and email or telephone ahead for appointments.

> *It's just about planning things and just being aware of whatever … If you stopped in a town for a little while and you knew you were going to be remote for a while, you just make sure you go to the doctor and get a new script and get a couple of repeats or whatever on the pills or whatever and then you've got them when you need them* (Eric).

> *I just do a search on the internet to find out who's the nearest town, where is one* [general practitioner] *and then ring up and make an appointment* (George).

Planning expertise

Participants planned travel routes that took into account weather, social commitments and health needs, as well as places of interest. They explained how they specifically developed strategies for planning and organising their routes according to need. Most participants reported taking trips for at least 6–12 months' duration for several years at a time. Jack struggled with the heat and thermo-regulation following treatment and had a strategy for this;

> *We looked online and I said, where's the coolest town in Australia right now [during a particularly hot summer] and it was Esperance. So we said, right let's go there. So we did. That was about 1500 kilometres to Esperance and we went* (Jack).

> *We tried to be back in Brisbane around Christmas every year … when we were in the area to have any tests done that we needed to have done* (Norma).

Many participants described how they organised medication and cancer and health treatment histories as documents to carry with them.

> *I got on the net and researched the local GPs and picked the one I wanted and made an appointment — had an initial long appointment so she got my history — I always travel with a patient summary from my GP in Adelaide* (Freda).

Managing cancer treatment on the road: it's not a big impact

Some participants were managing ongoing treatment such as oral chemotherapy, whilst travelling and had incorporated this into their daily life on the road.

> *The surgery removes the damaged organ, the ongoing treatment maintains a vigilance and my ongoing medication* [oral chemotherapy] *keeps me on a level playing field … I know I need to have the medication and I put in place strategies to deal with that …* (Clara).

Maintaining treatment regimens required organisation and planning; to get the medications prescribed; and to acquire and store them:

> *Thalidomide, being a controlled drug obviously, you had to organise from the hospital to send that through to you by post* (Bettina).

> *… My GP's very good and of course, you've got 12 months to use them up I think. So I make sure I've got a full box when I travel — when I start out — and a prescription to top up when I go along the way* (Clara).

> *Well, my medication has to be refrigerated, so that had to be taken into consideration — that we had refrigeration or some way of keeping it cool — and those sorts of things. But it was not that big an impact* (Andrea).

Cancer follow-up: just another component of the travel plans

Cancer treatment frequently requires follow-up for various durations depending on the cancer, treatment and response. The follow-up requirements for attendance and tests had the potential to restrict the nomadic lifestyle of participants but, as experts in their nomadic lifestyle, they integrated the demands of follow-up into their everyday life:

> *It's not difficult. There's nothing to manage. You've got — as I said, the only thing I've got to worry about is getting the —*

now the four monthly blood test — so my next blood test's not due for another three months now (Bettina).

Where necessary, they developed strategies to manage their follow-up:

I have small doses of irradiated iodine every year up until now and a full body scan and then that's being stretched out now because my levels are marking quite well. So it's ongoing checks to see if the cancer returns (Clara).

I have prostate cancer which was treated and I … have checks every six months on my PSA [prostate specific antigen] *levels* (George).

The strategies frequently demonstrated an acceptance on the part of the treating team that the participant was an expert in their own survivorship and a relationship with them that acknowledged and facilitated this. The collaborative way of working was the norm:

We just make appointments over the phone and then when they tell us we've got to be back in the Cairns area, we just make sure we're in a capital city and get a flight up. That's all (Debbie).

I checked with my specialist before I left Adelaide and his comment was, when your mammogram's due, have one wherever you are and if the results are not good, give me a call (Freda).

He [the haematologist] *told me to watch out for pins and needles in your feet and your hands. So, once that started happening, I just emailed him and said, oh you said not to take the drug any more. So that was it. He said, yes. We'll talk about it when I see you next and that was it* (Bettina).

Travelling because of a cancer diagnosis

For some participants, the diagnosis of cancer had been the catalyst for travel. The priority for participants became to follow their dreams, despite any potential risks of travelling independently or boundaries posed by cancer treatment and its sequelae:

I still had a massive big scar across my throat and yes, I said, I'm going. I need to get out there and I need to do things … suppose in some ways it made me think I don't have long to live, so therefore let's live life (Andrea).

I just think, well do as much as you can while you can. So that's why we're doing this one (Bettina).

My diagnosis was — in a way it was a blessing that it happened because it was a wake-up call — made me change a lot of aspects of my life and made me realise that life is precious and that we should seize every opportunity to do the things that we want (Norma).

Travelling healthfully

Participants described how their decision to travel and nomadic lifestyle contributed to their healthful survivorship:

We actually felt that our health all improved while we were travelling. … I mean we were probably similarly active, but we felt that our health significantly improved while we were travelling — both physically and emotionally (Martha).

Going out and living life to the fullest, is going to make you a happier person, which is going to make your immune system stronger, which is going to make you more able to fight any further cancers (Norma).

Being proactive in looking after their general health was important and participants explained the importance of this and illustrated their expertise in crafting a healthful way of living. They described strategies, planning and organisation for active health promotion for healthful survival and well-being:

Mental health is really important because once you let your mental health slip, then your physical health will be affected as well (Andrea).

You have to look after yourself. You have to make sure that you eat as well as you possibly can, because some places you go to you can't buy fresh fruit and vegetables and things like that. So that's important for good health (Andrea).

We always make sure we've got our flu shots now because we're both 70 this year (Clara).

Discussion

This study has shown that participants engaged with a nomadic lifestyle as part of a healthful response to living on from cancer diagnosis. These findings challenge those of Raven and of Tate *et al.*[4,34] who reported evidence of inadequate preparation for travelling, including lack of health summaries, inadequate medication supplies and unplanned hospital admissions.

The way that grey nomads normalise life and live on after a cancer diagnosis and can successfully navigate their survivorship provides a new contribution to the literature. A cancer diagnosis may not be a barrier to a nomadic lifestyle and, for some, it is the catalyst for it. Cancer survivorship has been described as a life-changing experience because it prompts people to re-prioritise what is important in their lives[9,10,13,14,35,36] or may include adopting a new sense of purpose in life[9–11,15]. Experiencing a 'new normal' may mean adopting a new lifestyle that is focussed on health and wellness[8,37,38] as is demonstrated by the narratives of some participants in this study. Understanding health behaviours such as those described by participants in this study have been cited as a priority area in survivorship research[18].

The concept of *living on*[21] sought to capture the 'going-on-ness' of participants' lives and the way in which they accommodate the disruptions[39] and chaos created by the changes inherent in being a person diagnosed with a life-threatening or chronic condition. Over time, these changes to their body, their identity, their way of life — in other words to their environment — become part of

the everyday fabric of their lives. Many participants explained that the diagnosis of cancer was their catalyst to travel. This is consistent with experiences of grey nomads living with chronic conditions[3]. In the discourse on survivorship, *living on* is analogous to the 'new normal'. The 'new normal' frequently refers to a transformation in the individual following a cancer diagnosis that can be experienced in a number of domains. The embodied 'new normal' — the way in which people experience their survivorship — comprises the realisation that returning to the old normal may not be easy or possible. Furthermore, it includes adaptation to this fact.

The way that participants talked about the ordinariness of living with cancer and managing both cancer treatment and follow-up suggested that they have normalised their cancer survivorship as a component of their nomadic lifestyle. They have adapted to a changing environment, both with regard to their travel and to their health. Participants became experts in managing both their health needs and their travel needs. They knew how to do things and how to navigate the health system to manage their treatment and follow-up, whilst on the road. As people living on and after a cancer diagnosis with all of the implications that go with that, they adapted to their environment on the road. These changes to their environment had become part of the everyday fabric of their lives.

Canguilhem[40] argued that "health" was essentially the ability of the person to accommodate the challenges posed by a new environment by creating new norms. Good health, Canguilhem[40] argued, "means being able to fall sick and recover" (p. 199).

The environment changed catastrophically for both participants with cancer and their primary support persons. The functional norms that participants adopted, both as cancer survivors and as nomads, were different to their previous norms or the norms of others who did not have cancer or who were not living a life as a nomad. Being diagnosed with cancer and becoming long-term travellers demanded new responses from participants to their environment and a new relationship with it. Participants were actively seeking to experience health by travelling.

Participants chose a healthful lifestyle[27] in that they sought autonomy and chose to immerse themselves in the world. Participants talked of strategies but talked little of struggle or difficulties or symptoms of their cancer, or treatment sequelae or of any difficulties related to their health and being on the road. They simply evaluated the situation — the changes to their environment — and responded with planning and strategies. Participants created their own strategies to work in partnership with health professionals (rather than rely on them) to evaluate risk, monitor their bodies and manage their healthful lifestyle. In doing so, they demonstrated expertise in their planning and organisation. In other words they integrated the work of cancer survivorship[41] with their everyday work of travel. This is in keeping with other literature describing the increasing active role that people living with cancer and other chronic conditions are required to undertake[41].

Limitations

As purposive sampling was used in recruiting participants to the initial survey phase via social media sites and caravanning forums and groups, potential participants without internet access were not able to participate in the survey and thus the interviews. Participants who consented to interview may have been more confident and articulate and thus able to develop partnerships with health care providers, which was crucial to participants' self-management and ability to travel and manage cancer treatment and follow-up.

Conclusion

A nomadic lifestyle of grey nomads with cancer can be a healthful choice and thus health promoting; it is a normalising process as explained by the concept of living on and also supports a broader notion of healthfulness within cancer survivorship. Participants were living healthfully in that they were living a lifestyle that promoted their well-being. The grey nomads participating in this study developed strategies in response to their changed environment and thus created new capacity to support their goals, projects and aspirations and they — with planning and organisation — were able to do what they wanted to do. Despite being cancer survivors and, for some participants, having cancer treatment with its attendant adverse effects, participants gained 'health' through their chosen nomadic lifestyle.

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