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The Patient

THE MANY FACES OF PREVENTATIVE CARE IN THE PRACTICE OF ONCOLOGY

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Abstract

Prevention in the oncology setting has traditionally focused on the progression of cancer, recurrence and development of new cancers. Increasingly, the focus has moved to a more holistic view of prevention that pursues prevention of suffering and maintaining quality of life. The cancer treatment team has the opportunity to play an active role in the promotion of healthy lifestyles for patients, and the relatives for whom the patient's cancer conveys risk. Assisting patients to adhere to 'non-cancer' care is important for their mortality and morbidity. Given patient's reluctance to disclose physical and emotional side-effects they may be experiencing, there is a need for health providers to regularly initiate discussions with their patients about their needs. Similarly, an oncology service that actively seeks to understand patient preferences will be better equipped to provide individualised care. A systems-minded approach to prevention may ensure that cancer care is organised to anticipate and to prevent of poor quality care. As the cancer treatment team will continue to play a more complex role in prevention, they must be supported by organisational factors that facilitate evidence-based practice.

An ounce of prevention is better than a pound of cure. This principle is as important in the practice of oncology as it is in primary care. The cancer treatment centre plays a leading role in the patient's health care during diagnosis, treatment and post treatment follow-up care. Traditionally, 'prevention' in this setting has focused on preventing the progression of cancer, cancer recurrence and development of new cancers. However, the focus has moved to a more holistic view of prevention that pursues prevention of suffering and maintaining quality of life.¹ This article examines the role of the cancer treatment centre in providing holistic preventative care to patients and their families across the cancer journey. Section one describes primary and secondary prevention of physical and psychosocial issues in cancer patients, including preventing comorbid non-cancer conditions. Section two explores the role of the treatment centre in preventing future cancer diagnoses of relatives for whom the patient's cancer conveys risk. Section three proposes a systems-minded approach to prevention and explores organising

cancer care in anticipation of patient needs and prevention of poor quality of care.

Primary and secondary preventative care

Is there a need to prevent physical co-morbidities?

Focusing on the long-term health of individuals diagnosed with cancer is essential, as almost 60% of those diagnosed live beyond five years post-diagnosis.² Cancer patients are more likely to have pre-existing medical conditions and are also at risk for the development of comorbid conditions including cardiovascular conditions, osteoporosis and diabetes.^{3,4} Cancer patients have a 50% higher risk of mortality from non-cancer causes compared to the general population, primarily due to coronary heart disease and stroke.³ However, a cancer diagnosis may divert attention from non-cancer health problems.⁵ Cancer survivors are often undertreated for chronic medical conditions such as diabetes, heart failure, as well as receipt of recommended preventive services including cholesterol screening,

influenza vaccination, bone density measurements and cervical cancer screening.⁵⁻⁸

Cancer and other chronic medical conditions, such as heart disease, share many risk factors including smoking, poor diet and physical inactivity. Reducing risk factors by changing lifestyle factors may be protective against the development of other chronic disease,⁹ however only 20% of oncologists provide patients with guidance about lifestyle change.⁴ When comparing lifestyle risk factors between individuals diagnosed with cancer and the general population, Australian cancer survivors are more likely to be smokers (particularly those with tobacco related cancers),¹⁰ slightly more overweight or obese and have higher levels of alcohol consumption. Levels of physical inactivity and fruit and vegetable consumption are not different.¹⁰

Is there a need to identify patient side-effects early?

The vast majority of cancer patients undergoing treatment will experience one or more side-effects as a result of their cancer and treatments. Up to 90% will experience fatigue,¹¹ 33% of patients undergoing curative treatment and 64% of advanced cancer patients will experience pain,¹² and 33-45% will experience psychosocial distress.¹³ Despite guidelines outlining optimal management of side-effects,^{14,15,16} almost one in two patients with cancer-associated pain is undertreated,¹⁷ fatigue is not addressed in almost 40% of cancer patients,¹¹ and between 12-85% of cancer patients report unmet needs for psychological issues.¹⁸ Detection of patient concerns is the first step towards appropriate and effective management of issues, however health professionals do not accurately recognise the physical and psychosocial problems that their patients are experiencing.^{19,20} Patients may be reluctant to disclose issues without prompting from a health care provider.^{21,22} Undetected and untreated side-effects result in unnecessary suffering and may also escalate in intensity over time. Patients experiencing pain are significantly more likely to be depressed.²³ Similarly, depressed patients are less likely to adhere to medical advice and treatment recommendations, which in turn can lead to poorer physical outcomes among patients.²⁴

What can the cancer treatment team do?

The cancer treatment team have the opportunity to play an active role in health promotion across this cancer trajectory by taking advantage of the 'teachable moment' that a cancer diagnosis provides,⁴ and through better management of their patient's non-cancer health care.²⁵ Asking about current health behaviours is the first step to promoting a healthy lifestyle.²⁶ Appropriate referral and/or provision of information should follow.²⁶

To ensure that the survivor's health needs are met, the Institute of Medicine has recommended that survivorship care should focus on coordination between the cancer treatment team and primary care providers.²⁷ Survivors who are observed by both a general practitioner (GP) and their cancer treatment team are most likely to receive recommended care for their non-cancer issues.^{6,7} The cancer treatment team could be informed of their patient's non-cancer medical history and emphasise to patients the importance of managing non-cancer illnesses. Asking the

patient about their contact with other health care providers, such as GPs, may be the first step. When the cancer care is the only routine health care provided, the cancer treatment team should take action, by providing an appropriate referral. Documenting these activities in the patient's medical record is important, and may serve as a prompt for future consultations.

Given patients' reluctance to disclose their physical and emotional problems, there are benefits in health providers regularly initiating discussions with their patients about their needs. Health care providers may need to provide patients with 'permission' to discuss their issues by encouraging questions, and providing adequate information.²⁸ One proposed way forward has been routine screening for psychosocial and physical issues via self-report surveys and providing summary data to the cancer treatment team. However, while routine screening systems have demonstrated efficacy, effectiveness of these interventions in regular clinical practice has not yet been established.²⁹

Prevention of cancer in family members for whom the patient conveys risk

The patient's cancer may implicate increased risk for their family members, as a result of a hereditary cancer predisposition or shared lifestyle factors. Key health promotion strategies for at-risk family members include cancer surveillance and targeting lifestyle factors for both patients and family members.

Is there a need to prevent cancer in the first degree relatives of patients?

While cancer risks are greater in the first degree relatives of cancer patients from a variety of cancer types,³⁰ the survival benefits of surveillance are only evident for relatives of colorectal, breast and melanoma patients.³¹⁻³³ First degree relatives of patients may be classified as average risk where surveillance recommendations correspond with the general population. Other relatives may be classified as moderate or high risk where more intensive surveillance is recommended.³¹⁻³⁴ Screening for a genetic mutation may be appropriate when confirmation of a strong family history is obtained,³⁴ however only a small subset of cancers (5%-10%) can be attributed to specific cancer causing genes.³⁴

In Australia, there is no population-based approach to identify and target at-risk relatives of individuals diagnosed with cancer. Identifying at-risk family members depends on the actions of individual health professionals. This relies upon family history taking, yet incomplete records are a common occurrence.^{35,36} Colorectal screening rates remain low in Australia despite having the best evidence for reducing mortality, with only 18% of individuals aged over 50 tested using the faecal occult blood test (FOBT) within the last five years. Relatives of cancer patients are 20% more likely to be tested with FOBT.³⁷ Only one-fifth of Australian family members with a strong family history of melanoma met National Health and Medical Research Council screening guidelines, with less than 60% ever having received a recommendation from a health professional to conduct skin self-examination or receive a clinical skin examination.³⁸ Mammographic screening in high risk women is conducted according to guidelines in 74% of cases, with the remaining 16% being under-screened and 10% over-screened.³⁹

Is there a need to prevent cancer in the spouses of patients?

Spouses' lifestyle behaviours and physical health often correspond. Concordance has been found between spouses' smoking status, body mass, diet and presence of high blood pressure.^{40, 41} There is modest evidence that spouses may share risk factors for lung, bladder and stomach cancers.⁴² While no specific guidelines exist for promoting lifestyle factors in the spouses of patients, general population lifestyle recommendations apply.

In the oncology setting, little is known about whether lifestyle interventions are routinely directed to patients only, or to the family unit. However, in the cardiovascular setting, dietary interventions are commonly targeted to both the patient and their spouse. To date, there is insufficient research about whether family-based interventions are any more or less effective than individually focused interventions at changing health behaviours.

What can the cancer treatment centre do?

A cancer diagnosis not only offers a teachable moment for the patient, but also for the family member for whom the patient's cancer conveys risk.⁴³ While it may be argued that relatives do not fall within the duty-of-care of cancer treatment centres, targeting relatives has the potential to indirectly benefit the patient and impact in a positive way on the lives of both patients and their families.

Given the potential survival benefits of surveillance for colorectal, breast, ovarian cancer and melanoma, attention should be paid to first degree relatives of these cancer patients. Risk levels may be readily identified based on the patient's family history. Verbal and/or written information about cancer risk, and appropriate screening recommendations, could be provided to the relative or to the patient to pass on to their relatives. Families with suspected hereditary cancers should be referred to familial cancer services and encouraged to join their state-based hereditary cancer registry to facilitate surveillance. As patients often worry about whether their family member might be at risk,⁴⁴ discussion with patients about risk levels of their first degree relatives may help to meet this unmet need. Furthermore, accessing an at-risk family member via the cancer patient will help to overcome some of the problems with inaccuracies in self-reported family history.⁴⁵

For patients who have unhealthy lifestyles, it is possible that the spouse may share these risk factors. Therefore, promotion of healthy lifestyle behaviours to both the patient and spouse could double the reach of these important health messages.

System based prevention

The health care system is largely reactive, waiting for trouble before responding.¹ Rather than a reactive health care system that responds at the point of crisis, the Institute

of Medicine envisions a system that organises the delivery of care in anticipation of the needs of patients.¹ It is argued that a health care system of this nature would be more patient-centered.¹ Patient-centered care is a central aim of quality health care and is founded on the idea that health care should not simply cure disease, but relieve suffering and maintain quality of life. Patient-centred care must: a) support the provision of information, communication and education to enable patients to understand and make informed decisions about their care; b) attend to consumer needs, values and preferences; c) provide emotional support; d) relieve physical discomfort; e) allow for the involvement of family and friends; and f) be integrated and co-ordinated.⁴⁶ While patient-centered care is important in and of itself, it is also associated with increased adherence to treatment plans, more efficient care, and improved quality of life.⁴⁷⁻⁵⁰

There are a number of ways we might ensure that the oncology service anticipates and meets the needs of cancer patients. The first is to actively understand the preferences and values of each individual patient in order to provide individualised care. Doing this is likely not only to meet patient needs, but also increase patient satisfaction and trust in their health provider, and the service that they receive.^{51 52} The second approach is to prepare the patient for future problems or issues with which they will have to deal, by providing information and an explicit response plan to prevalent and treatable problems.²⁵ The third approach focuses on the way in which the system is currently responding, and by gathering data, anticipate and respond so that any system deficits can be addressed.⁵³ This third approach reflects the Institute of Medicine's emphasis on optimising the quality and productivity of the health care system,⁵³ whereby measurement of system functioning is essential for quality improvement activities.

What can the cancer treatment team do?

Oncology services should actively seek to understand patient preferences for future care delivery. Examples of scenarios where seeking patient preferences is fundamental to the delivery of quality cancer care include: 1) advanced care planning, which involves seeking patients preferences for end of life care; 2) shared decision making, whereby the clinical knowledge of the provider is considered alongside the preferences, values and needs of the patient, to arrive at the best decision for patient; and 3) life expectancy discussions, whereby patient preferences must be sought regarding the level of information they would like to receive. Figure 1, describing advanced care planning, has been used to illustrate the role of the oncology service in actively seeking a patient's preferences to prevent poor delivery of care. This scenario contrasts a model of care that reacts during a crisis with an anticipatory model that seeks to understand patient preferences ahead of time. The benefits of the anticipatory model are evident for the patient, their family and the health system.

Figure 1: Advanced care planning, an example of reactive versus anticipatory care.⁵⁹⁻⁶²

Advanced care planning	
Reactive care	Anticipatory care
Intensive end of life cancer care provided to all patients.	End of life cancer care consistent with the patients preferences, values and beliefs.
Family members or health care providers make decisions about end of life care after the patient's health has deteriorated.	Patients are consulted about their preferences ahead of time, before deterioration of health.
Patients asked once about their end of life preferences.	Continuous discussion between patient, family and health provider about end of life care, as preferences change over time.
Patient preferences not documented.	Patient preferences clearly documented.
Avoiding discussion about end of life care.	Promoting ongoing end of life care discussions that may include informal discussions with family and providers; formal legal documents, appointment of a substitute decision-maker.
Poorer patient quality of life	Higher patient quality of life.
Poorer bereavement outcomes for the caregiver.	Better bereavement outcomes for the caregiver.
Higher health care costs.	Lower health care costs.

Oncology services should anticipate and respond to system deficits at a systems-level.

A quality cancer treatment centre is “one which is both organised around and responsive to the needs of the people who use it”.⁵⁴ Patients should receive best practice cancer care, irrespective of the treatment centre they attend, or the health care provider they visit.¹ However, if we wish to better meet the needs of future patients and reduce inequities in the delivery of care, first we must understand the current level of care being delivered to patients.^{1, 55} This information can be used to respond to system deficits.

Assessing delivery of care on a regular basis is essential for identifying deficits in best practice cancer care, and for monitoring progress towards clearly defined goals.^{1, 55} The Australian Commission on Safety and Quality in Health Care has recommended that systems be put in place to regularly collect information about patient-centred outcomes.⁵⁶ The gold standard for assessing patient-centred outcomes is patient self-report.¹ Most Australian states administer periodic pen-and-paper surveys to subsamples of patients to track quality of care over time. However these surveys are limited in their ability to provide feedback that is both timely and specific. These two essential ingredients would enable individual cancer treatment centres to target their quality improvement activities.⁵⁷ One solution may be for cancer treatment centres to routinely survey their own patients.⁵⁶ The use of information technology, such as tablet computers to collect and automatically analyse data, has the potential to provide real time feedback.

Conclusion

The practice of oncology in the 21st century has moved to a more holistic view of prevention. Not only can the oncology service successfully treat patients for their

cancer, but by delivering optimal cancer care, can relieve their suffering. Cancer care has moved beyond the acute stage of cancer treatment, towards the long-term care of a growing number of survivors with a ‘chronic’ cancer condition. Consequently, the cancer treatment team will continue to play a more complex and expanding role in the delivery of cancer care. To date, a focus on changing the behaviour of individual health care providers via single vector mechanisms, such as distribution of clinical practice guidelines or education seminars, has been insufficient to improve the delivery of care.⁵⁸ The future of prevention in cancer care may look towards a systems-minded approach to improve the delivery of health care, whereby organisational factors, such as the structure and process of the cancer treatment, are modified to approximate evidence-based practice.⁵³ Future research should be conducted to identify what environmental or system-based changes would facilitate better delivery of patient-centered care.

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