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Juggling cancer and life in survivorship

The role of general practitioners

CPD 

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Background

The number of cancer survivors in Australia is growing. General practitioners (GPs) have a key role in providing holistic care to people experiencing a cancer diagnosis, receiving treatment or enduring long-term effects of cancer and its treatment. Cancer survivors experience a range of unique biopsychosocial issues, requiring significant and coordinated care to optimise their quality of life.

Objective

The aim of this article is to provide an overview of management strategies for GPs in addressing three highly distressing cancer-related issues: fear of cancer recurrence, financial toxicity and management of relationships.

Discussion

Recommendations are provided for effective screening and monitoring of cancer-related issues, with management strategies outlined to facilitate GP-initiated discussions and referral to credible resources and other health services. Useful materials relevant to the Australian primary care setting are presented together with an overview of information to support GP provision of cancer survivorship care for fear of cancer recurrence, financial toxicity and relationship issues.

IMPROVEMENTS IN CANCER SCREENING, diagnosis and treatment have led to a rapid increase in the number of cancer survivors (ie people living with and beyond a cancer diagnosis) worldwide.^{1,2} This growing population places enormous demand on the healthcare system to address morbidities and manage wide-ranging cancer survivorship issues, including detection of recurrences, health promotion, surveillance and management of physical and psychological symptoms and side effects, financial concerns, and problems with relationships and social wellbeing.³ This article focuses on addressing fear of cancer recurrence,^{4,5} financial toxicity^{6,7} and relationship issues,⁵ which are some of the most under-addressed yet common psychosocial issues confronting cancer survivors.

Enhancing the involvement of general practitioners (GPs) in survivorship care has been proposed as a key strategy to improve the quality of follow-up care for people living with and beyond cancer.⁸ The three key types of follow-up models for people who have completed their primary treatment include cancer specialist-led care (ie oncologists, haematologists, cancer nurses), GP-led care and shared-care (ie follow-up care shared between cancer specialists and GPs to collaboratively manage complex needs of cancer survivors).⁹ Current models of post-treatment care in Australia are mostly cancer specialist-driven and focus on surveillance for disease recurrence rather

than the holistic care needs of cancer survivors. To address the complex needs of cancer survivors, it is critical that GPs and cancer specialists (including surgeons, oncologists, cancer nurses, allied health professionals and psycho-oncologists) partner to offer their different skill sets and expertise.

General practice is an appropriate setting for a range of survivorship interventions when GPs are properly supported through the provision of relevant information, quality tools and clear communication. This ensures GPs can effectively deliver a range of cancer survivorship interventions in general practice, including but not limited to disease-specific surveillance assessments, physical examinations, and the assessment and management of psychosocial issues.¹⁰⁻¹² Indeed, GPs are more likely to address psychosocial issues, promote healthy lifestyle behaviours and manage other acute and chronic health conditions, compared with cancer specialists.¹¹ GPs have a day-to-day role in addressing psychosocial issues of their patients using their existing counselling skills. They can facilitate access to subsidised GP Management Plans, Team Care Arrangements and Mental Health Treatment Plans (MHTPs)¹³ that underpin chronic disease management and referrals, and facilitate access to established networks of community-based allied health practitioners. There are also opportunities for social

prescribing (linking clients to community support services) to help improve patient wellbeing.¹⁴ In addition, GPs often have a longer-term relationship with patients (and potentially their family members), placing them in a unique position to deliver high-quality psychosocial care. Accordingly, GPs are well placed to address commonly experienced and under-addressed issues affecting cancer survivors within primary care.

The aim of this article is to provide an overview of the experiences and management strategies for fear of cancer recurrence, financial toxicity and management of relationships in the primary care setting.

Managing prognosis uncertainty and anxiety

Experiencing some worry in response to the potential threat of cancer recurrence is somewhat inevitable and can be used to help motivate positive behaviour changes to reduce recurrence risk.¹⁵ These worries resolve naturally in some cases, although one in three cancer survivors will report serious fear of cancer recurrence (FCR) that warrants clinical attention,¹⁶ with women and younger cancer survivors at increased risk. Clinically significant FCR is characterised by high levels of worry or preoccupation, and hypervigilance to bodily symptoms that persists for three months or more.¹⁷ FCR has been linked with greater physical symptoms and greater use of primary care,^{4,18} thus frequent unscheduled GP visits by cancer survivors in response to symptoms may indicate underlying FCR.⁴ FCR is not consistently related to clinical variables such as disease stage, treatment type or time post-treatment, and it typically will remain stable or become more severe over time without clinical assessment and intervention.¹⁶ FCR is related to anxiety, depression and poorer quality of life in cancer survivors; it may be exacerbated in those with a history of psychological conditions, thus it is important to be extra vigilant and proactive in addressing FCR for people at risk.⁴

Screening and management strategies for FCR, along with useful resources for

GPs, are presented in Box 1. Validated tools such as the nine-item Fear of Cancer Recurrence Inventory – Short Form (FCRI-SF) are often used to identify clinical FCR (cut-off score ≥ 22) in research settings.¹⁹ There is no widely used screening tool for the detection and monitoring of FCR in clinical practice, but validation of a single-item FCR tool for clinical use is currently underway.²⁰ In the interim, asking cancer survivors about their FCR is a useful and necessary first step towards identifying FCR. Normalising FCR as a common and reasonable concern may help redress mild FCR in some cancer

survivors. Some GPs may already routinely address FCR, but evidence suggests that many healthcare practitioners do not raise the topic of FCR with patients.²¹ It is important that GPs initiate these conversations, as cancer survivors may not readily express their concerns because of worries about seeming judgemental of their care.²¹

GPs have expressed uncertainty regarding how to effectively manage FCR and concern that asking cancer survivors about FCR may provoke unnecessary worry; however, this has been shown not to occur.²¹ GPs are well

Box 1. Fear of cancer recurrence (FCR) screening and management strategies with resources for general practitioners (GPs)

Screening strategies

- Routinely ask the question: 'How worried are you about your cancer recurring?'
- Validated screening tools to identify and monitor FCR (eg the Fear of Cancer Recurrence Inventory – Short Form).
- More vigilant screening for patients with pre-existing psychological conditions
- More vigilant screening of high-risk populations: women and younger people

Management strategies

- Education for cancer survivors and carers to clarify risk of recurrence
- Access to GP Management Plan and Team Care Arrangement as appropriate
- Psychological interventions (eg cognitive behavioural therapy)
- Self-management strategies, such as:
 - discuss fears with others or write letters thanking them for their support
 - be aware of which symptoms may indicate cancer recurrence
 - attend scheduled follow-up appointments
 - keep entertained with hobbies and enjoyable activities
 - form or join an existing support network
- Positive lifestyle behaviours to reduce risk of recurrence, such as:
 - eat a well-balanced diet
 - exercise regularly
 - get adequate sleep
 - avoid smoking, non-prescribed drugs and too much alcohol
- Discuss appropriate frequency of cancer screening (as recommended by guidelines) to aid early detection of recurrence
- Referral for those with persistently high FCR to a clinical psychologist (consider use of Mental Health Treatment Plan)

Useful resources

- Fear of Cancer Recurrence Inventory – Short Form: Screening and monitoring tool in research, www.cfp.ca/content/66/9/672/tab-cfplus
 - ConquerFear: Repository of Australia-specific information on FCR for clinicians and survivors, www.pocog.org.au/content.aspx?pagetype=public&page=fcrhub&version=1&search=*
 - Australian Cancer Survivorship Centre: Information sheet on FCR self-management strategies, www.petermac.org/sites/default/files/ACSC_FactSheet_Fear%20of%20Cancer%20Coming%20Back_WEB.pdf
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equipped to implement management strategies, support cancer survivors to adopt self-management strategies and engage in positive lifestyle behaviours, and promote recommended cancer screening and follow-up. GPs can also provide ongoing information, similar to interventions provided by oncologists,²² such as clarifying risk of recurrence (which is often overestimated) while reminding cancer survivors of specific symptoms of cancer recurrence and how to respond if symptoms are observed.²² To facilitate this, patients' estimated risk of recurrence should be included in discharge summaries/survivorship care plans shared with GPs. Including GPs in discussions regarding complex cases involving FCR during multidisciplinary team meetings may also be helpful. In the future, cancer survivors will be able to access FCR interventions such as the Australian-developed 'ConquerFear' or other psychological interventions (ie contemporary cognitive behavioural therapy and group-based programs) shown to significantly reduce FCR.^{23,24} An FCRI-SF score ≥ 22 (refer to Box 1 for URL) may offer a useful threshold for referral to these psychologist-delivered interventions.

Managing employment and finance

Financial distress or hardship associated with having cancer, also known as financial toxicity, is a global and significant issue, even in countries such as Australia that have universal healthcare systems.^{6,7} A systematic review including 25 studies of 271,732 cancer survivors reported financial toxicity ranging from 28% to 48% using monetary measures (eg medical out-of-pocket expenses as a percentage of total household income) and 16% to 73% using self-report measures (eg impacts on everyday living expenses).⁷ Since the publication of this systematic review, six domains of financial toxicity have been conceptualised to help identify and characterise the issue: 1) active financial spending, 2) use of passive financial resources, 3) psychosocial response, 4) support seeking, 5) coping with care and 6) coping with lifestyle.²⁵ Common risk factors for

financial toxicity include high costs of medications, supportive care therapies, adjuvant therapies, transportation, low pre-diagnosis household income and younger age.²⁶ Other risk factors include absenteeism from work during treatment, a limited ability to return to work after treatment^{26,27} and earlier-than-planned retirement.²⁸ Understandably, financial toxicity negatively affects the emotional wellbeing, physical symptoms and quality of life of cancer survivors.^{29,30}

Screening and management strategies for financial toxicity, along with useful resources for GPs, are presented in Box 2. Financial toxicity should be routinely screened for using validated screening tools and regularly discussed openly with cancer survivors and their significant others.³¹ Multifactorial interventions addressing financial toxicity also benefit from early referral of cancer survivors to additional support services, such as not-for-profit organisations offering resources and support groups.^{31,32} Limited legal and financial expertise can also be accessed, with the demand for these services to increase as the number of cancer survivors also rises.¹ A recent qualitative study³³ investigating GP perceptions of their role in addressing financial toxicity in cancer survivors suggested that while solutions to manage financial toxicity require a multidisciplinary approach, the GP can have an important role as part of the cancer care team. However, limitations to this role include the lack of knowledge about diagnosis and treatment costs, the complexity of cancer care, the GP's role in the cancer care team, and varying perceptions of health service and care provision.³³ Accordingly, GPs would benefit from improved cost transparency of a range of treatments, better communication from cancer specialist teams and more accessible information about financial support as priorities. Further investigation is required into how general practice and community services can be efficiently coordinated, to clarify roles and address gaps in knowledge that will better enable GPs to respond to patients and disseminate information promptly.³³ Another important strategy

to enhance team integration and communication between cancer specialist teams and GPs in the post-treatment phase is the use of survivorship care plans, which can further inform GPs' plans to address financial concerns (eg return to work plan, ongoing medical costs).³⁴

Managing relationships

Cancer is a life-changing diagnosis and event – not only for the cancer survivor, but also their immediate and extended family, children, friends, work colleagues and social contacts, all of whom experience a period of adjustment in the survivorship phase. During reintegration into family, intimate relationships, work and social networks after a cancer diagnosis, there is often a disconnect between life before and after cancer for the survivor and their significant others.³⁵ On the other hand, it is possible to foster closer relationships, shared perspectives about future directions, increased personal strength and resilience, and improved lifestyles and behaviours after together facing the major life challenge that cancer presents.^{36,37} However, concerns about relationship difficulties, sexuality, intimacy and psychological worries rank highly as unmet needs among cancer survivors.⁵ If family relationships, sexual function, financial circumstances and vocational issues were tenuous prior to the diagnosis, the cancer experience has the potential to cleave fault lines and lead to serious and persistent dysfunction, especially if differing expectations, communication styles and coping styles exist. Higher levels of unmet needs and psychological morbidity are also likely to be seen in vulnerable groups such as people in regional or rural areas, older cancer survivors, culturally and linguistically diverse survivors, and those with premorbid chronic physical and/or mental health problems.^{38,39}

Strategies and useful resources for GPs to assess and manage relationships for cancer survivors are presented in Box 3. In addition to cancer survivors, their care providers also have supportive care needs; therefore, giving attention to the psychological needs of family members and carers is an integral part

Box 2. Financial toxicity screening and management strategies with resources for general practitioners (GPs)

Screening strategies

- Use validated screening tools (eg Comprehensive Score for Financial Toxicity – Functional Assessment of Chronic Illness Therapy [COST-FACIT]) to identify and monitor for financial toxicity (www.facit.org/measure-english-downloads/cost-english-downloads)
- More vigilant screening of high-risk populations

Management strategies

- Maintenance of a doctor–patient partnership to advocate and facilitate robust and knowledgeable conversations about financial concerns and available support services
- Cost transparency of services ensuring conversations are led by the GP and support the patient to engage in conversations about costs of diagnosis and treatments with other health professionals
- Development of a return-to-work plan
- Use of cancer Optimal Care Pathways to support appropriate and transparent decision making
- Use of cancer survivorship plans with a multidisciplinary team approach; and use of team case conferencing to facilitate communication between acute cancer care team and general practice
- Access to GP Management Plan, Team Care Arrangement and Mental Health Treatment Plan as appropriate
- Early intervention through referral to practical and financial assistance via local and state/territory cancer support services (eg the Cancer Council via telephone on 13 11 20)
- Where appropriate, assistance with patient access to superannuation for terminally ill patients

Useful resources

- Australian Cancer Survivorship Centre (ACSC) fact sheet: Dealing with money, work and study (practical issues), www.petermac.org/sites/default/files/media-uploads/ACSC_Factsheet_DealingWithMoneyWorkStudy.pdf
- Cancer Council Australia: Informed financial consent, www.cancer.org.au/health-professionals/resources/informed-financial-consent
- Cancer Council Australia: Cancer and your finances (booklet), www.cancer.org.au/assets/pdf/cancer-and-your-finances-booklet#_ga=2.59877284.802044400.1623973480-972410339.1613957205
- Cancer Council Australia: The financial cost of healthcare (booklet), www.cancer.org.au/assets/pdf/financial_cost_of_healthcare_Patient_Information
- Cancer Council NSW: Help with bills (factsheet), www.cancercouncil.com.au/wp-content/uploads/2020/03/Help-with-bills_NSW.pdf
- Cancer Council NSW: Dealing with debts (factsheet), www.cancercouncil.com.au/wp-content/uploads/2020/03/Dealing-with-debts.pdf
- Canteen Australia: Money matters, www.canteen.org.au/youth-cancer/treatment/practical-stuff/money-matters
- Centrelink, www.servicesaustralia.gov.au/individuals/centrelink or via telephone on 13 27 17
- Victorian Department of Health and Human Services: Concessions and benefits, <https://services.dffh.vic.gov.au/concessions-and-benefits>
- Moneysmart: Urgent help with money, <https://moneysmart.gov.au/managing-debt/urgent-help-with-money>
- Financial Counselling Australia, www.financialcounsellingaustralia.org.au
- Cancer Council Victoria: Cancer wellness – Life management, finances and work (webinar), <https://vimeo.com/343127590/2bb8385c1b>
- Cancer Council NSW: How will I manage financially? (webinar), www.youtube.com/watch?app=desktop&v=K8wxLVjcJTl
- Flinders University: Work after Cancer, www.workaftercancer.com.au/welcome

of comprehensive survivorship care. Cancer survivors and their significant others rarely voluntarily acknowledge their ongoing physical and emotional distress, raising the importance of GPs initiating confidential, non-judgemental discussions regarding relationships. An important part of these discussions is identifying factors that may strain relationships, such as the provision of care for elderly parents, the presence of sexual dysfunction, psychological morbidity, adolescents with behavioural or mental health concerns, as well as employment displacement or financial toxicity.^{38,39} For example, couples experiencing ongoing sexual dysfunction respond well to a clinician-initiated discussion about the changes they are experiencing in intimacy and sexuality, the provision of information resources, and referral to other specialists including menopause services, urologists, fertility services or qualified sexologists.⁴⁰ Generally, GPs play an important part in providing point-of-care counselling and facilitating referral pathways for MHTPs, local community-based services, online services or back to psycho-oncology teams to build resilience and support self-management of ongoing relationship concerns.⁴¹

Conclusion

Fear of recurrence, financial toxicity and relationship concerns are common and debilitating issues among cancer survivors that can be effectively screened for, and managed, in primary care settings. GPs are well positioned to address these issues effectively. Routine screening using validated tools (where available) and onward referral to relevant professions (ie psychologists, sexologists, financial advisers) are recommended. Evidence-based resources and pathways canvassing diverse issues affecting cancer survivors and their significant others should be developed and implemented for GPs in the primary care setting.

Key points

- GPs are well positioned to provide cancer survivor follow-up care.

Box 3. Strategies and resources for general practitioners (GPs) to assess and manage relationships of cancer survivors

Screening strategies

- Confidential, non-judgemental GP-initiated discussions
- More vigilant screening of unmet needs for high-risk populations:
 - people in rural or regional areas, older or culturally and linguistically diverse people, and people with premorbid chronic physical or mental health problems

Management strategies

- Promote development of self-management strategies and self-management support
- Provide community-based and online support services
- Use Mental Health Treatment Plans (MHTPs) for individual, couple or family counselling:
 - under the Better Access initiative, MHTP to provide access to mental health clinicians
- Access to GP Management Plan and Team Care Arrangements as appropriate
- Referral to accredited sexologist for people with persistent dysfunction in intimate relationships

Useful resources

- Cancer Council Australia: Information on support groups, podcasts, online communities, www.cancercouncil.com.au/advanced-cancer-podcasts/managing-relationships-as-the-carer
- Carer Gateway: Information sheets, links to support services, and counselling for carers, www.CarerGateway.gov.au or via telephone on 1800 422 737
- Young Carer program: Information and support for carers under 25 years of age, www.carerswa.asn.au/our-services/young-carers
- Society of Australian Sexologists: Online database of accredited Australian sexologists for referral, www.societyaustraliansexologists.org.au

- Fear of cancer recurrence, financial toxicity and relationship issues are highly prevalent and under-addressed among cancer survivors.
- Validated screening tools and the use of open-ended questions are recommended for the detection, management and monitoring of these survivorship issues.
- GP-initiated discussions and point-of-care counselling are recommended to address fear of cancer recurrence, financial toxicity and relationship issues.
- GPs play a key role in referring cancer survivors to appropriate health resources and specialised health services.

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