

# CARE OF OLDER PEOPLE LIVING WITH CANCER: THE ROLE OF THE SPECIALIST NURSE AND ALLIED HEALTH PROFESSIONALS

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## Abstract

Older people with cancer have unique physiological, psychological and social needs. This article has identified several key actions that can readily be integrated into existing cancer care services to improve care outcomes for older people referred for cancer treatment, namely: embedding an integrated assessment into the initial visit to ensure early identification of symptoms and unmet needs; monitoring the effectiveness of cancer treatment and changing needs; optimising function through early and appropriate referral; maintaining GP contact; ensuring the provision of well-coordinated care; addressing psychosocial, emotional and financial needs; and minimising caregiver burden.

Emotional distress, lack of social support and medical issues are just some of the many issues faced by the older person living with cancer. As the population ages and the number of older people diagnosed with cancer increases, the challenge for the health care system is how it will adequately identify, address and manage this population's physical, psychological and social needs, as well as those of their caregivers, many of whom are also older. Having recognised this unmet need, a number of large international and national cancer services have developed geriatric oncology programs. While many cancer care services may aspire to develop these specialist programs, the reality is that few will have the capacity. Yet, there are practical steps cancer care services can implement today to ensure that the needs of older people with cancer are better addressed. This article provides insights into the nursing and allied health interventions that can be readily integrated into usual cancer care practices to address priority concerns for older people recently diagnosed with cancer and their caregivers.

Cancer is predominately a disease of older people. Many older people present with more advanced cancer and have comorbidities and pre-existing limitations over multiple domains which impact on their functional ability, nutritional status, cognitive function and emotional wellbeing.<sup>1</sup> In the US, unmet emotional support needs, caregiver burden, transportation issues and the need for in-home assistance are frequently cited concerns of older people living with cancer.<sup>2</sup> In Australia, similar concerns have been identified across all age groups, with only 40% of cancer patients and even fewer carers perceiving that they had received the services they required to improve their psychological wellbeing, including coping with stress, anger, depression, isolation and uncertainty.<sup>3</sup> Despite there being increasing recognition that older people with cancer have unique care needs, the research focus has been on screening and assessment issues, as opposed to proactively addressing unmet practical and psychosocial support needs.<sup>4</sup>

In a small number of larger Australian cancer care centres the unique needs of older people with cancer are being addressed through the establishment of designated geriatric oncology programs and advanced geriatric oncology medical and nursing positions. In addition to the tailored supportive care offered by these services, the establishment of designated geriatric oncology roles enables these clinicians to have input into multidisciplinary meetings, ward consultations and ad hoc inquiries, as well as undertake research and provide clinician education. While it is acknowledged that not all centres will have the capacity or the need to create designated geriatric-oncology services, there are opportunities within the existing system to strengthen the care provided to older people with cancer and their caregivers. This article provides insights into the nursing and allied health interventions that can be readily integrated into usual cancer care practices to address priority concerns for older people recently diagnosed with cancer and their caregivers.

## Continuous assessment and monitoring

Both the US National Comprehensive Cancer Network and the International Society of Geriatric Oncology recommend that some form of geriatric assessment is integral to optimising cancer care for an older population.<sup>5,6</sup> Despite this recommendation, debate regarding what constitutes the best form of geriatric assessment for older people referred for cancer treatment continues. While there is currently little consensus as to what the optimal geriatric oncology assessment should look like, there is agreement that the gold standard Comprehensive Geriatric Assessment (CGA) is of little benefit to the older person and their caregivers if identified issues are not addressed. The CGA was originally designed to predict functional decline and falls in an older population with cognitive and functional impairments. A CGA helps assess the unmet supportive care needs and other interventions required to optimise the health and wellbeing

of the older person and their caregivers. In an ideal world, undertaking a geriatric assessment to inform appropriate cancer treatments, timely identification and addressing of areas of concern, and ongoing integrated and coordinated care, would be incorporated into usual care for older people diagnosed with cancer.

In the non-cancer population, utilising a formalised assessment process to identify an older people's unmet needs and putting in place appropriate multi-disciplinary interventions is not a new concept.<sup>7</sup> There is evidence that screening, assessment and targeted follow-up care for older people, that combines physical, psycho-educational and psychosocial intervention, increases survival and reduces unplanned hospital presentations. In a large cohort (n=739) of older Australians aged over 75 years presenting to an emergency department, an intervention involving an initial assessment of functional and mental status, combined with a home visit within 24 hours, development of a care plan, activation of interventions and referrals, resulted in significantly lower rates of admission to hospital during the first 30 days after the initial emergency department visit. There were also lower rates of emergency admissions in the 18-month follow-up period and a longer time to first emergency admission.<sup>7</sup>

Similarly, a nursing-led intervention involving comprehensive clinical assessment, monitoring and skills training for older post-surgical cancer patients (n=375), implemented during three home visits and five telephone contacts over a four week period, also resulted in improved overall survival.<sup>8</sup> In patients with advanced disease, the two year survival in the intervention group was 66.7%, compared with the control where it was 39.6% ( $p < 0.05$ ).<sup>8</sup> This randomised control trial was the first to link nursing interventions to improved survival for older people with cancer in the post-operative recovery period.<sup>8</sup> Improved survival and hospital avoidance are not only desired by older people, but are important measures of health economic outcome improvement, as well as being indicators of coordinated care.

### Care coordination

While traditionally, the delivery of cancer services has been primarily hospital-based, there has been greater emphasis on the provision of multidisciplinary care in the community setting. This shift has increased the need for improved communication and coordination, and has coincided with the establishment of cancer care coordinators across Australia. These coordinators, along with specialist cancer nurses, play a central role in promoting continuity of care, ensuring that patients don't feel isolated and know how to navigate their way through the system and across care settings in order to access the care they require in a timely manner.

Specialist cancer nurses are also ideally placed to ensure that older people and their caregiver(s) understand the importance of the GP continuing to be involved in the older person's medical management, especially their chronic disease management, as well as their ongoing cancer care.<sup>9</sup> However, to be effective in this role, GPs need complete and timely information from the treating cancer team,

clinical information as well as social information, including an overview of the information provided to patients and their relatives about their illness covering side-effects of treatment, rehabilitation, prognosis, and role of the family.<sup>10</sup>

Cancer care coordination for an older population frequently involves many long face-to-face conversations with patients and their caregivers. The treatment decision-making process for older cancer patients is complex and requires multi-dimensional assessments to classify the patient's fitness for chemotherapy and to determine an appropriate treatment plan.<sup>11</sup> It also requires provision of evidence-based information to the person with cancer, so they can make informed decisions about their capacity to tolerate the proposed treatment and the implications of such treatment on their long-term health and well-being. These conversations often involve the translation and layering of information previously provided by other clinicians. Older people frequently struggle to fully comprehend the rationale for various treatments, especially adjuvant therapy.<sup>12</sup> Cancer care nurses play a crucial role in ensuring older patients and their caregivers understand the implications of these treatment recommendations.

Older people also require self-care management strategies, provision of emotional support, practical coordination and information about multiple appointments. Providing effective care to older people often requires greater liaison with a larger number of health professionals who are involved in the management of the older person's care, such as the aged care assessment team, the general practitioner, community nurses and other chronic and complex illnesses specialist nurses or care teams.

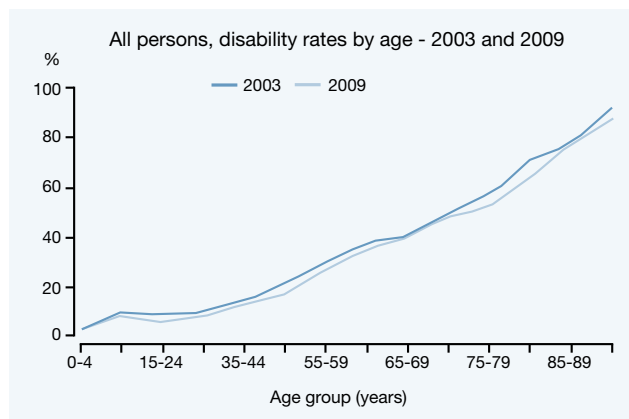
### Emotional support

Many older people experience social isolation and financial hardship and require psychosocial support related to cancer treatment decision-making, coping with their illness in general, as well as treatment.<sup>13</sup> An early social work referral is often indicated if a lack of social supports and access to practical support is found to be a determining factor for older people declining or withdrawing from treatment.<sup>14</sup> While transportation challenges are not confined to the older population, it is a frequently cited concern for older patients and their caregivers, who themselves are often elderly. Providing transport and parking assistance, including access to disability parking, allows older people who are still driving to retain some of their independence and relieves the burden on caregivers in a physical and financial sense. Older patients from rural and remote areas face more difficulties in accessing specialist care in terms of transportation and timely referral.<sup>13</sup>

### Optimising function

Disability increases steeply with age (figure 1). It has been estimated that 48% of all newly diagnosed older cancer patients have performance limitations as measured by activities of daily living (ADL), compared to 40% of the overall elderly population.<sup>15</sup> The administration of systemic cancer treatment to older people increases the likelihood of further functional decline.<sup>15</sup>

Figure 1: ABS level of disability increases with age.<sup>16</sup>



An older person's instrumental activities of daily living (IADL) score prior to the commencement of cancer treatment is predictive of outcomes, with independence associated with higher quality of life and improved overall survival, and dependence linked to higher risk of chemotherapy related toxicities.<sup>17</sup> Making functional status one of the strongest predictors of overall survival in the geriatric cancer population.<sup>17</sup>

Previous research has identified that while older people desire active treatment aimed at prolonging their life, they also want to optimise their functional ability and quality of life.<sup>13</sup> A study involving a cohort of older women with metastatic breast cancer identified that the greatest remedial effects could be gained if appropriate interventions were provided as soon as ADL deficits were identified.<sup>18</sup> Assessing and monitoring older cancer patients' functional capabilities requires the introduction of systems and processes that can continuously monitor and respond to these changes. Given the increasing numbers of older Australians diagnosed with cancer, this is a potentially onerous task for a sole practitioner. However, geriatric oncology nurses, or tumour stream specific nurses, are ideally placed to undertake the geriatric screening, assessment and monitoring role.

A specialist cancer nurse, being visible at the point of care and having the capacity to work across the acute and ambulatory cancer care settings, ensures that older cancer patients are appropriately assessed, the necessary interventions implemented in a timely manner and ongoing monitoring provided. While providing direct and indirect clinical nursing expertise, the strength of these specialist roles lies in the nurse's capacity to engage on a needs basis with other multi-disciplinary team members, including the general practitioner. Assisting the older person and their caregiver(s) to navigate the health care system and access the care and supports required to optimise care outcomes is an essential element of the specialist cancer nurse role.

Occupational therapists are invaluable in promoting optimal function in personal and instrumental ADLs, by adapting task or improving the capacity of the person to perform.<sup>19</sup> Being aware of an older person's pre-treatment level of function and arranging occupational therapy input as soon as functional decline is experienced, helps optimise the older person's functional capacity. While previous research has

demonstrated functional impacts of cancer and age related comorbid conditions, there is limited evidence surrounding the exact impact that chemotherapy has on patient function in specific ADL. Having systems in place to continually assess the older person's evolving need for practical support is crucial, as their functional abilities rarely improve during their cancer journey.<sup>20</sup> An intervention commonly arranged by specialised nurses and allied health professionals is referral to in-house allied health professions or community-based services. These community based state and government funded schemes provide vital practical assistance that allow older people to access supportive interventions such as allied health services (podiatry, physiotherapy and occupational therapy), domestic help (cleaning, washing and shopping), personal care (showering and dressing) and home modifications that assist safe mobilisation. Accessing these services frees caregivers up to attend to other tasks.

Nutritional concerns regarding the older person with cancer is both common and multi-factorial.<sup>21</sup> It requires early interventions that involve assessments of obvious deficits as seen in cancer of the upper gastrointestinal tract and head and neck cancers, evaluation of oral health and dentition, swallowing ability, a review of impacting co-morbid conditions, medication review, psychosocial support and cognition. In the instance of weight loss, a referral to a dietitian is commonly recommended, as halting this decline is complex and often requires expert skill and intervention. Another area of expert intervention is the field of pharmacology, in particular the challenging area of treatment individualisation, careful use of supportive agents such as anti-emetics and haematological growth factors, knowledge regarding potential drug interactions and poly-pharmacy and medication rationalisation.<sup>22,23</sup> The co-existence of various chronic medical conditions also makes the treatment and management of cancer and treatment-related effects more complex, with diminished organ function increasing the risk of toxicities and adverse effects from poly-pharmacy.<sup>22,23</sup>

When discussing care options and treatment plans, it is important to be mindful of the impact hearing and vision impairment have on communication, and the impact of advancing age on health literacy.<sup>24</sup> Identifying and minimising the impact of these aged related factors is particularly relevant in the context of older people needing to implement various treatment and symptom management self-management strategies at home, ranging from adherence to oral chemotherapy regimens, mouth care and being vigilant and attending to febrile episodes. The complexity of many of these self-management regimens demands the active engagement and input of older peoples' caregivers and their inclusion in patient education sessions.

### Caregiver input and support

Ensuring that caregivers receive the information they require is critical to them being able to support the older person with cancer. Australian carers report not receiving all of the information they need to care for the person receiving cancer treatment, not feeling more than half didn't feel informed enough to know how to deal with side-effects of treatment or the patient's overall health.<sup>25</sup> In geriatric oncology, caregiver input, along with the patients preference, is crucial

to determining the goals of care and devising an optimal treatment plan.<sup>26</sup>

The caregiver role is a complex task that may have physical and mental repercussions.<sup>27,28</sup> Increasingly care-giving responsibility is falling to people aged 65 years and older. The impact of having an older caregiver is amplified if they too have health issues and/or a disability.<sup>29</sup> Being the caregiver of an older person with cancer is not only physically demanding, but has an emotional toll.<sup>30</sup> Several studies suggest that the spouse caregiver of the older patient with cancer may be at even higher risk for depression than the patient.<sup>31,32</sup> A caregiver's health status, age, patient's symptoms and functional ability (ADLS and IADLS) have all been associated with caregivers of older people newly diagnosed with cancer experiencing depression.<sup>32,33</sup> Being mindful of the age of carers is crucial, as are the demands on a caregiver's free personal time, their changing social roles, the potential for a decline in their physical and mental wellbeing and strains on financial resources. A recent age and gender matched study exploring coping and distress among spouse caregivers to older cancer patients, found that men utilise less active coping strategies than women.<sup>28</sup> It is important for clinicians to tailor recommendations and interventions that assist caregivers with gender preferences incorporated.<sup>34</sup>

If the caregiver is also employed, they may need to spend time away from work, especially if the patient requires assistance with IADLS, which has financial implications.<sup>30</sup> In addition to providing practical assistance and emotional support, clinicians can improve the caregiver experience for those caring for older people living with cancer through: improved communication; better coordination of the patient, clinicians and caregivers schedules; and better symptom and medication management education.<sup>30</sup> Early identification of older people with increased needs will help reduce caregiver burden and reduce the potentially detrimental effects of care giving.

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