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Providing leadership through patients as partners: Improving Australian colorectal survivorship care through perspectives from a nurse who became a cancer patient

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Abstract

Objective: To provide contemporary real-world, real-life insights into gaps in supportive care experiences for people affected by colorectal cancer. For the first time, this article includes a patient as a co-author, with the aim to identify future priorities to improve care and recovery in colorectal survivorship care.

Data Sources: Electronic databases, peer-reviewed literature, real-life professional and personal experiences.

Conclusion: There are several problematic areas in providing supportive care for people affected by colorectal cancer, that could be improved by wider access to colorectal specialist nurses, co-ordinated multidisciplinary teams, patient collaboration, linking survivorship care outcomes to national standards, and developing supported self-management care plans.

Implications for Nursing Practice: A patient-led insight has underscored some fundamental failings in current service delivery among people affected by colorectal cancer. Partnering with consumers in research and service re-design is essential to stratify future priorities to optimise care and person-centred recovery.

Key words: colorectal, bowel, cancer, partnering with patients, leadership, unmet needs; survivorship

Introduction

Colorectal cancer is Australia's second deadliest cancer behind lung cancer and the third most commonly diagnosed cancer behind breast and prostate cancer [1]. The five-year survival rate is 71% and it is estimated that there are 55,387 people currently living with colorectal cancer [1]. However, these statistics do not capture the total number of Australians living with the long-term complications from their colorectal cancer and its associated treatment.

With the improvements in early detection and more effective treatment regimes, there are more people living beyond their diagnosis than ever before [2,3]. However, as the number of colorectal cancer survivors increase so does the number of patients living with long-term side effects from their cancer and treatment that require supportive care [3-5]. Post-operative complications can occur in up to 50% of all individuals affected by colorectal cancer and are directly associated with reduced quality of life [6]. It is therefore not surprising that as the incidence of cancer increases, so too does the health resource burden and associated healthcare expenditure [2,6].

Despite the increasing number of colorectal cancer survivors, there is a paucity in research on colorectal cancer symptoms, self-management and evidence informed guidelines to support patients to live well beyond diagnosis; to not just survive cancer, but to thrive [7]. Many individuals and their families affected by colorectal cancer experience unmet needs, but little has been done to effectively partner with patients to develop and implement effectual survivorship services to address what matters most to them [2].

Cancer is increasingly being viewed as a chronic condition with growing evidence that the effects of cancer and associated treatment can impact patients for years after treatment [8-10]. Colorectal cancer and treatment side-effects impact individuals in all domains of life, commonly including bowel and urinary dysfunction, financial toxicity, unemployment, psychological morbidity, fatigue, negative body image, relationship breakdown, sexual dysfunction, early menopause, fears of recurrence, peripheral neuropathy, challenges with stoma self-management, cognitive impairment, insomnia, weight loss, and an overall reduction in quality of life [4,7]. Yet, there is an increasing emphasis on patients to self-manage the impacts of cancer and treatment, with encouragement to reach out for support only when they feel it is required [11]. This approach to care can be viewed as a reactive rather than an anticipatory model of care.

Key priorities in Survivorship care

My experience from the patient perspective

At the time of my cancer diagnosis in 2018, I was a 38-year-old Clinical Nurse Consultant with 18 years of experience as a Registered Nurse. I became one of the 15,713 Australians diagnosed with colorectal cancer that year. Despite having excellent acute medical care, I experienced several cancer and treatment-related side effects which included bowel dysfunction, nausea, weight loss, fatigue, food intolerances, challenges with the psychological adjustment to cancer, and parenting strain while managing my roles as a patient and mother to young children.

I experienced substantial gaps in my survivorship care. I was discharged from hospital after my surgery, with a scheduled post-operative review and routine surveillance follow-ups. I did not receive any education or information on possible cancer and surgical side-effects; I also didn't receive any routine post-operative referrals to allied healthcare professionals such as a dietitian, exercise physiologist or psychologist; nor did I receive a documented care plan to guide me in my recovery from my cancer and its treatments. The care gaps that I experienced were as a result of systemic gaps in embedded processes of standardised support, education, and care coordination for colorectal cancer patients.

I had to seek out and organise my own expert multidisciplinary team, often through trial and error, despite my many years of experience as a Registered Nurse. I was living in a reactive healthcare loop, where I would present to my General Practitioner with my unmanaged symptoms to organise support to cope and alleviate my distress. I was drained and lacked the cognitive stamina to seek out clinical guidelines, so instead I would 'Dr Google' my symptoms wondering "*am I normal*", "*what's wrong with me*", "*when will this end*", "*why am I not getting better*"? My post-operative journey would have been made easier if I had received routine evidence-based pre-operative and post-operative co-ordinated multi-disciplinary care.

Eventually, I managed to find health experts who could support me to manage my side effects, build my function, and help me to improve my quality of life. I was informed that my side effects were in fact not only "normal", but also common. As my stamina increased, so did my interest in improving the health outcomes and quality of life for all colorectal cancer patients in Australia. I knew that as a health system we could do better and overcome the many unmet supportive care needs that sadly many patients and their families experience. Integrating my real-world, real-life insights with available evidence, below are the key recommendations into how it may be possible to optimise multidisciplinary cancer care to improve the delivery of patient-centred evidence-based survivorship care, in an effort to reduce long-term morbidity and improve the quality of life of colorectal cancer patients.

1. Nationally funded specialist Colorectal Cancer nurse roles to provide needs-based survivorship care

We have an excellent opportunity in Australia to develop a nationally funded colorectal cancer nurse program. Paving the way in recognising the value of specialist cancer nurses, the Australian government has invested $82.2 million (GST exc) in the McGrath Breast Care Nurses Program from 2007-08 to 2022-23, $41.2million (GST exc) in the Prostate Cancer Nurses program from 2013-14 to 2022-23, $4.8 million (GST exc) in the Ovarian Cancer Australia for the Teal Support Program from 2018-19 to 2023-24, and $900, 000 (GST exc) in the Lung Foundation Australia for the Cancer Care Nurses Program in 2021[12]. Considering the burden of colorectal cancer outlined above, and the 15,713 Australians newly diagnosed with colorectal cancer each year, nationally we have a well-defined and increasing patient population who need specialist cancer nursing support.

Specialty nurses in survivorship care play an important role in supporting patients to manage treatment side-effects and improve follow-up compliance [13]. A recent study [4] found that almost two out of three colon cancer patients and nine out of ten rectal cancer patients, reported long-term unmet needs after their treatment. Similarly, in a study of 526 colorectal patients, over 60% of patients reported five or more moderate to severe unmet needs at 24 months post treatment related to physical, psychological, health system and information needs [14]. Furthermore, a study representing 872 colorectal patients found that approximately 40% of patients had poor confidence in managing their cancer and treatment-related side-effects [11]. These findings are important because a person’s ability to self-manage their cancer and treatment effects is directly linked to improved recovery outcomes of patients, for which most individuals lack supported self-management guidance from healthcare professionals [10,11,13]. A recent study [15] of 200 patients identified that up to 20% of patients reported unmet information needs, financial strain, gaps in care coordination and concerns regarding cancer recurrence. There is a significant discrepancy between health professionals reporting that they provide advice, and the proportion of patients actually being able to recall this information [16]. Given the magnitude of unmet supportive care needs, specialist colorectal cancer nurses are ideally positioned to provide timely, accessible, and patient-centred informational support and education to guide patients throughout their survivorship [1,13,17]. Importantly, patients who can access a care nurse co-ordinator report having more of their needs met [17].

Patients require a greater awareness of the side-effects of cancer treatment. By working in partnership with patients, health care teams can develop and increase the commitment to create new models of care for patients, by raising awareness and addressing what matters most to them[18]. Patients who experience long-term side effects have difficulties in adhering to lifestyle modifications including dietary adjustments and regular exercise due to their unmanaged side-effects [19], and a lack of access to multidisciplinary healthcare professionals.

In summary, a specialist colorectal cancer care nurse would be well positioned to:

- provide patients with education and resources pre- and post-treatment to improve the patient's knowledge, set recovery expectations, and support self-management abilities
- action early referrals to appropriate allied health professionals including dietitian, stomal therapist, exercise physiologist, pelvic-floor physiotherapists, social worker and psychologist to prevent, reduce and manage side effects
- link patients into local survivorship networks
- provide education on, and aid compliance with surveillance regimes as well as provide education on lifestyle modification in an effort to reduce cancer recurrence

2. Multidisciplinary specialised support services

Often cancer specialist nurses in other tumour groups provide the hub of survivorship care safely embedded in the multidisciplinary team (MDT) [20]. Colorectal cancer care is complex and requires coordinated, multidisciplinary care from medical specialists, nursing and allied health professionals [19]. As an example, bowel dysfunction is a common colorectal cancer and treatment side-effect, encompassing diarrhea, urgency, faecal incontinence, bloating and constipation [16]. When combination treatments of extensive abdominal-pelvic surgery, pelvic radiation therapy, chemotherapy and surgical resection are needed, patients can experience substantial bowel dysfunction, sphincter loss, and a permanent stoma [7]. The negative impact of these side effects can be long-term and include sexual dysfunction, psychological morbidity, reduced physical performance, social consequences and insomnia for which recovery interventions administered by a MDT are paramount [21].

Further emphasising the complexity of colorectal cancer management a 2020 meta-analysis of 35 studies [7] found that body image distress, gastrointestinal and psychological symptoms, insomnia, and peripheral neuropathy were the most commonly reported side effects. The breadth of these side effects further highlights the need for a well-co-ordinated MDT to optimise patient-centred care and rehabilitation. Additionally, it is important that healthcare providers acknowledge that there are patients who are more at risk of experiencing adverse effects related to cancer and its treatments including females, younger adults [22], individuals treated with oxaliplatin-based chemotherapy, those with a stoma, rectal cancer patients, individuals with low education levels, low self-efficacy, those living alone, those with co-morbidities including psychological disorders, and those with poor baseline physical health [4,7]. Those patients who are most at risk should be identified early and supported by a co-ordinated MDT as soon as possible, ideally at the time of diagnosis.

Lastly, the 2021 Australian Optimal Care Pathway for people with colorectal cancer outlines that supportive care is an essential element of any cancer care program and should be based on the unmet needs of the patient [1]. The pathway emphasises the central importance that all MDT members have a role in optimising supportive care across the entire cancer care continuum with particular focus on key transition events such as diagnosis, prehabilitation, during and after treatment, rehabilitation, and survivorship, to end-of-life and bereavement care.

3. Clinical Care Standards for standardisation of survivorship care

So, the question is, how do health care providers and service developers move from acknowledging the contemporary evidence and clinical guidelines to the standardised implementation of robust patient-centred care practices, in order to proactively prevent and manage these unmet needs of colorectal cancer patients? One solution to be considered is the development of a Clinical Care Standard for Cancer Survivorship Care. The Australian Clinical Care Standards are linked to the mandated National Safety and Quality Health Service (NSQHS) Standards [23] and aim to reduce unnecessary variation in care delivery. Such a standardised approach could outline the type of care that patients should be offered, regardless of the geographical location of where they are treated. Partnering with patients in research and clinical service design is central to the NSQHS [23].

The Clinical Care Standards describe the care that patients should be offered by their treating clinicians and health services for a defined clinical condition, in alignment with the current, available best evidence[24]. When hospitals are assessed for accreditation, this process confirms that the relevant systems have been implemented to ensure that the expected standards of safety and quality are met. At the time of writing this article, there are 16 Clinical Care Standards, including the Colonoscopy Clinical Care standard within the Australia Healthcare setting [24]. A Clinical Care Standard for Cancer Survivorship Care would help to address the variation in colorectal cancer care. This is important, as a recent study [25] identified that only 30% of cancer patients reported that they had received a written treatment summary and instructions for follow-up care. The majority of patients articulated that they did not receive information about recurrence, late effects of cancer treatment, fertility issues, cancer recurrence, and familial risk [25]. Whilst considering the contemporary evidence outlining the increasing national incidence of colorectal cancer, the prevalence of colorectal cancer, treatment side effects, and the associated health care costs, it is reasonable to reflect on the benefits of developing a National Clinical Care Standard for Cancer Survivorship Care as well as the equitable and consistent implementation of such as standard.

4. Patient Resources

While contemplating the current evidence and in reflecting on my own lived experience, my greatest piece of advice for colorectal cancer patients and their carers, in the absence of nationally funded colorectal cancer nurses and in the absence of a Clinical Care Standard for Cancer Survivorship Care, is to link in with a MDT team and cancer support organisation who can provide you with evidence-based advice to proactively prevent and/or manage your cancer and treatment side effects.

Bowel Cancer Australia has a number of excellent resources, from their online survivorship network 'The Movement', to their Peer-to-Peer support program and their 'The Bottom Line Podcast' (Available from: https://www.bowelcanceraustralia.org/).

Additionally, as a result of my own lived experience as a colorectal cancer patient who experienced a number of unmet needs, I decided that I wanted to give back to the cancer community. I knew that if I, a highly educated health professional who was able to clearly articulate my health needs and advocate for support, experienced many challenges throughout my recovery related to unmet supportive care needs, then I wondered how non-health professionals were able to navigate their recovery. To that end, I wrote my first book, a book 'A Woman's Guide to Navigating the Invisible Cancer Load' (Available from: https://theawakenedmumma.org/product/a-womans-guide-to-navigating-the-invisible-cancer-load-paperback/).

In my book, I have unpacked my own recovery experience, shared words of wisdom from the cancer community and have collaborated with healthcare experts to help shed light on some of the lesser discussed, yet greatly important impacts of cancer and recovery. I have covered the topics of parenting through recovery, nutrition myth-busting, exercising through symptoms, carer strain, financial strain, cancer fog, body image hurdles, end-of-life discussions, returning to work, and how to deal with the greatest mindset shift of my life. These are the survivorship challenges that I commonly hear discussed in cancer communities, and although not acutely life threatening, they certainly impact our quality of life and capacity to return to a fulfilling and rewarding life after cancer.

Cancer Navigation Top Tips:

Navigating cancer like any major life challenge, can be made easier with helpful advice from someone who has walked the path ahead of you. My best advice for someone who is starting out on their cancer journey is:

Emotional support

- Link in early to a cancer psychologist or counsellor – emotional support is key throughout your recovery.
- Remember that it is ‘normal’ to need emotional support when treatment has ended, and you are getting ready to go back to work or resume your ‘new normal life’. This is a period of deep reflection and processing of ‘what on earth just happened to my life’. This can take patients and loved ones by surprise.
- Encourage your partner and older children to link in with a specialist cancer counsellor as cancer impacts the entire family unit.
- Cancer recovery takes a village – so ask for help.
- Say “yes” to help, for you and your family.
- Call in your ‘A-Team’ – your closest friends, family, colleagues, and community supports who uplift you when you are down, and who can assist you and your family with practical tasks. Support with meals, shopping, transport to appointments, company during chemotherapy, play dates for children, dog walking, etc, can be helpful during treatment or recovery.
- Write a list of tasks and delegate anything and everything that you feel comfortable to, and that allows you to focus on rest and your family.
- Consider exploring meditation if you haven’t already – it is a powerful tool to manage both the emotional and physical impacts of cancer and treatment.

Practical support

- If you have time, try to do some preparation before your treatment begins: stock up the freezer with home-cooked meals, automate bills, organise insurance and employment paperwork, and unsubscribe from any non-essential correspondence.
- Link in with an Accredited Exercise Physiologist (AEP). Prioritise exercise pre, during and post treatment to improve mood, reduce treatment side-effects, improve treatment response and reduce cancer recurrence.
- Link in with a Dietitian or Clinical Nutritionist pre, during and post-treatment. The value of adequate nutrition in cancer care cannot be overstated.
- Prioritise sleep. Everything is easier to deal with when you have had adequate sleep. Talk to your GP or oncologist if you are struggling with sleep.

Finances

- Link in with your hospital social worker or cancer organisation for a list of financial support options.
- Parents of young children may be eligible for subsidised childcare. This is very helpful during active treatment phases.
- Contact your Superannuation organisation early and discuss your entitlements and the required documentation.
- Ask your partner to check their Superannuation policy details as they may have an additional 'partner trauma cover', which can pay a lump sum figure.

Making big decisions

- Know that it is OK to seek a second opinion, especially when discussing complex treatment options or the end of treatment options.
- If you are interested in exploring clinical trials, ask your treating team for information.

Finally, cancer is a marathon, not a sprint. On the hardest days, have hope that an easier day is around the corner. This is when you need to lean into your 'A -Team' a cancer nurse specialist, and a cancer psychologist. Be kind to yourself and remember to take one step at a time, and deal with one challenge at a time.

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