Core components of a best practice First Nations cancer coordinator role

The health of Aboriginal and Torres Strait Islander peoples (hereafter, respectfully referred to as First Nations Peoples) is holistic and embraces social, emotional, physical, cultural and spiritual wellbeing.[1] This goes beyond the mere absence of disease and encompasses connection to land and place, traditional knowledge and healing, equity and social justice. Globally, there is a growing body of Indigenous-led cancer and health initiatives that use Indigenist research approaches and prioritise the needs, perspectives and cultures of Indigenous Peoples and communities.[2-5] These approaches acknowledge Indigenous Peoples' right to self-determination and Indigenous sovereignty.[6]

In Australia, the shift towards First Nations-led health initiatives in cancer care has the potential to positively impact cancer outcomes by promoting a more equitable, culturally safe and effective approach to addressing cancer and policy making with First Nations Peoples. However, there remains much to be done.

Cancer outcomes for First Nations Peoples in Australia continuously fall below the national standards of care.[7] Although the past decade has seen a reduction in cancer mortality rates for non-Indigenous Australians, the mortality rate for First Nations Peoples has increased by 12% in the same period.[8] First Nations Peoples have a higher incidence of fatal, screen-detectable and preventable cancers, are more likely than non-Indigenous Australians to be diagnosed at a later stage of their illness and have a higher likelihood of concurrent complex comorbidities.[9]

There are several, complex causes for the disparate cancer outcomes experienced by First Nations Peoples, including historical and current policy decisions that have been imposed (and enforced) without consent or consultation.[10] Although these disparities are multifaceted, they are exacerbated by ongoing barriers to access and engagement with high quality cancer care services. Research exploring First Nations Peoples' experiences and perspectives of cancer care cites multiple barriers, including fear or mistrust of mainstream health services,[11] experiences of racism,[12] health care staff with unconscious biases or limited cultural understanding,[13] being away from Country,[14] out-of-pocket costs,[15] and cultural beliefs or stigma around cancer that elicit feelings of shame and avoidance.[16,17] Engagement is worsened by miscommunication and a lack of care coordination within and between services.[14,18]

Positionality statement

Our team acknowledges the importance of reflexively considering and describing our own backgrounds, perspectives and values that we each contribute to the project.[19] The first author (MW) is a non-Indigenous palliative care researcher, MM is a First Nations health practitioner, JP is a non-Indigenous senior palliative care clinician and researcher, BL is a non-Indigenous senior palliative care clinician and researcher and GG is a First Nations senior health researcher. Co-authors MM and GG both identify as First Nations Australians. MM is a proud Gomeroi/Kamilaroi woman and GG is a proud Kamilaroi woman. The CONSIDER reporting criteria checklist for health research involving Indigenous Peoples[20] was completed for this article and can be found in the Supporting Information.

The need for culturally safe and responsive care coordination

Internationally, there is evidence that helping Indigenous patients navigate the health care system can improve the accessibility and timeliness of high quality health care for Indigenous Peoples.[21,22] The benefits of adding Indigenous patient navigator or coordinator roles include improved cancer screening adherence,[23] support in overcoming logistical barriers (appointment scheduling, transport, etc),[24,25] building trusted relationships,[26] and support in the consideration and recognition of Indigenous culture and traditional practices by health care professionals.[25,27] Recently in Australia, culturally safe and responsive care coordination has been outlined as best practice in *The optimal care pathway for Aboriginal and Torres Strait Islander Peoples with cancer* (hereafter, Optimal Care Pathways),[28] and state and national Aboriginal community-controlled health organisation (ACCHO) cancer plans.[29,30] The need for culturally informed care coordination has been identified in other Australian studies, particularly in terms of navigating the cancer care system, enhancing cultural safety and providing linkages between the community, family and hospital.[12,31] There has been growing momentum to develop and implement Indigenous patient navigation and coordination programs. However, to date, there is limited published evidence regarding coordination models in Australia.

In this perspective article, we propose a best practice model of a First Nations cancer coordinator (FNCC) role. This role was developed to align with the Optimal Care Pathways,[28] state and national cancer plans[29,30] and was informed by international literature and recommendations from existing patient coordinator programs in Queensland, Australia.[26] The role was developed by a First Nations community advisory group, including members with lived experience of cancer, First Nations health workers, senior First Nations researchers and senior cancer care clinicians. The role development was guided by these key principles outlined by Anderson and colleagues: First Nations leadership, a culturally grounded approach, respect, benefit to community, inclusive partnerships, and transparency and evaluation.[2]

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The First Nations cancer coordinator model

The proposed FNCC model incorporates patient-facing responsibilities and community engagement to provide continuity of culturally safe care between community-based and primary health care services. In this model and others,[26] it is advantageous for the FNCC role to be primarily within the hospital or cancer care service, to work collaboratively with multidisciplinary cancer teams and First Nations health units, support patients at appointments, and access clinical data. The core components of the role are described below.

Requirements to align with the needs and values of the local community

Before implementation of FNCC roles, it is essential to establish First Nations governance structures and processes for ongoing community consultation, to ensure that FNCC interventions meet the needs of local communities. Likewise, the FNCC role should be endorsed by and developed in consultation with First Nations health workers employed at target implementation sites. Many, but not all hospitals in Australia, have established Aboriginal hospital liaison officers (AHLOs),[33] who have deep and lasting relationships with the First Nations community and who provide a large umbrella of cultural support, including cultural expertise, advocacy and provision of access to culturally safe spaces, resources and support services. In addition, and separate to this, the FNCC can provide specialised support for cancer care that is complementary to the cultural support that the AHLO teams provide. As an identified role, the FNCC role should ideally be embedded within an existing AHLO unit, to ensure that the FNCC has access to cultural supervision and support.

Continuous, between-service coordination, at all stages of the cancer journey

The proposed FNCC role provides continuous, between-service support and coordination. Unlike many other health care roles that are typically bound to a particular treatment or care setting, the FNCC should be flexible to support patients at all stages of the illness course, both within and outside the hospital setting. Consequently, with FNCC support, patients and families can access a consistent and trusted point of contact throughout, thus preventing potential delays and navigation challenges that can arise from multiple points of contact within a fragmented cancer care system. Regular attendance at outpatient clinics and multidisciplinary meetings would enable the FNCC to connect with patients early and offer coordinated support before hospital attendance or diagnosis. FNCCs should be closely linked with local community health services and may receive referrals to see patients in the community, before they attend hospital. This would lessen hesitancy about hospital attendance and reduce the numbers of missed outpatient appointments. FNCCs could also support patients to attend telehealth appointments from a culturally safe location of their choice. When identified roles such as the FNCC are the first point of contact for patients and families in the hospital system, this sets the tone of their experience and facilitates ongoing trust.

Knowledge about cancer-specific needs

Bringing together cultural and cancer coordination expertise, the FNCC will have knowledge about the unique cultural, spiritual and practical needs of First Nations Peoples with cancer and their families. In addition to cultural wisdom, the FNCC will have cancer-specific knowledge, bringing these combined sets of understanding to enhance care delivery. First Nations patients often report feeling less guarded and more comfortable when they can speak to a First Nations health worker about their questions or concerns.[14] Accordingly, the FNCC's cancer-specific knowledge will be an essential resource for patients and families, ensuring that they have understood their treatment options and can make informed decisions. In addition, the FNCC would support patients to voice their concerns to their treating team or highlight these concerns on the patient's behalf. This ensures genuine self-determination, and the prioritisation of cultural needs in care plan discussions.

Strong connections with First Nations health workers and multidisciplinary cancer teams

The FNCC's combined cultural and cancer-specific skill set will be strengthened through strong and collaborative relationships with First Nations health workers and multidisciplinary cancer teams. Through collaboration with First Nations health workers and AHLO units, the FNCC can ensure that cancer patients have access to culturally safe spaces and resources within the hospital. Through collaboration with multidisciplinary cancer teams, the FNCC can stay up-to-date with treatment progress and assist with appointment coordination and follow-up. FNCC attendance at multidisciplinary meetings, where investigation and treatment pathways are discussed, means the FNCC can advocate for their patients, ensuring that cultural considerations are embedded in care plans. Working collaboratively alongside cancer teams will provide opportunities for knowledge exchange, whereby the FNCC can receive up-to-date information about patients' medical and coordination needs, and non-Indigenous staff members can improve their understanding of their patients' cultural needs and preferences.

Advocacy and education about cultural safety in cancer care

Through trusted and collaborative relationships with multidisciplinary cancer teams, FNCC roles may enhance the cultural capability of non-Indigenous staff, by creating environments where they feel more confident to ask questions and seek guidance on culturally appropriate practices. While the FNCC can guide the delivery of culturally informed cancer care, it is crucial to emphasise that cultural safety is not the sole responsibility of First Nations health workers — it is the shared responsibility of the entire organisation, across all levels of health care delivery. Importantly, this requires individual health care professionals and organisations to hold themselves accountable for culturally safe care, as defined by the patient and community.[33]

Conclusion

First Nations Peoples in Australia are entitled to culturally responsive and high quality cancer care. A cultural support and coordination model, such as the FNCC, has the potential to increase access to and engagement with high quality services, reduce anxiety and improve cancer outcomes for First Nations Peoples and their families. Based in the hospital setting to build and consolidate relationships with staff, it is important that the role has flexibility to support patients in the community and to attend telehealth appointments from patients' preferred locations. Most importantly, while this discussion has focused on the core components of a best practice FNCC model, future roles should be developed and implemented in accordance with the needs and perspectives of the local community. To better meet the needs of First Nations Peoples, it is essential that research, policy making and service provision are underpinned by principles of First Nations governance and empowerment, and build on the existing cultural strengths of the community.

The core components of the FNCC model, while specifically focused on cancer, may be a useful foundation for future work on improving the access and provision of culturally responsive health care for First Nations Peoples, and may inform the rollout of similar coordination roles in other specialties.

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Supporting Information

Additional Supporting Information is included with the online version of this article.