

Strategies for Effective Cancer and End-of-Life Communication with Indigenous Patients

55

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Key Points

- Strategies to improve cancer and cancer treatment, communication, and Advance Care Directives for Indigenous patients to facilitate informed choices about the uptake of optimal care pathways were identified.
- Experienced healthcare communicators shared the importance of culturally comfortable settings for consultation, the use of visual metaphors to explain new concepts, and utilizing Aboriginal interpreters when possible.
- Effective communication relies on understanding the cultural importance of family and community, and the context in which cancer is perceived, particularly when communicating sensitive topics such as end-of-life care.

Two studies sought to identify strategies to improve communication with Indigenous Australian peoples across the cancer journey (with respect, we use the term Indigenous Australians which encompasses Aboriginal and Torres Strait Islanders as appropriate). Ensuring that information from diagnosis, through treatment, to end-of-life care is provided in a culturally appropriate manner and is understood by Indigenous patients and their families facilitates informed decision-making about care and positive interactions with the healthcare system.

In the first of the two studies, healthcare professionals, some Indigenous, who regularly communicate cancer diagnoses and treatment options to Indigenous people were interviewed to determine the most effective communication strategies and settings. In the second, ongoing study, an Indigenous student undertaking a Masters of Philosophy of Public Health engaged with Indigenous individuals and community groups in yarning circles in order to better understand the low completion rate of Advance Care Directives among Indigenous patients and to explore preferences for end-of-life care planning.

A Qualitative Study of Cancer and Cancer Treatment Communication

Improving how cancer is explained to Indigenous Australians has been identified as a way to increase uptake of optimal cancer care pathways [1].

To better understand the most effective cancer and cancer treatment communication strategies, the first study included 23 semi-structured interviews with healthcare professionals who regularly engage in such communication with Indigenous patients in urban, rural, and remote settings [2, 3]. These professionals included nurses, medical practitioners, Aboriginal health workers, a radiation therapist, and administrative and public health professionals from two Australian jurisdictions (Northern Territory and South Australia).

While we acknowledge the differences between Indigenous cultural groups and individuals, six consistent themes emerged from our interviews.

Create a Safe Environment, Engender Trust, and Build Rapport

The environment or setting in which a conversation about cancer takes place is important in helping Indigenous patients feel comfortable. Outside spaces or larger indoor space with at least a view of the outdoors may be desirable. Sitting with, rather than opposite, the patient can be helpful, and matching the gender of the patient and provider may overcome cultural sensitivities that should be considered in the context of communication.

Beginning a conversation with topics that are important to the patient, such as home and family, will help to develop rapport and build trust. It is important not to appear rushed, to use plain language, and to clearly explain medical terminology in lay terms. Observing non-verbal cues and checking that the patient understands what has been said are vital.

It is also essential that the healthcare professional takes the time to allow the patient and their support network to communicate their preferences for treatment options. Healthcare professionals should avoid assumptions about group behavior and instead concentrate on the individual patient, thus catering to each patient's specific needs.

Employ Specific Communication Strategies to Explain Cancer and Cancer Treatment

The healthcare professionals we interviewed strongly emphasized the use of visual examples and familiar metaphors when explaining new concepts to Indigenous patients. For example, cancer might be illustrated as a tree with roots spreading underground and branches above, with scattering seeds representing cancer metastases. Similar visual aids can be extended to explain more challenging concepts such as adjuvant radiotherapy. For example, the healthcare professional might use the metaphor of pulling up weeds but not being sure that all the roots have been pulled out; thus, radiotherapy is used to kill any remaining roots so that the weeds do not sprout again. Similarly, the metaphor of a dammed creek might serve to explain obstructive symptoms.

Other metaphors for cancer in the body might include the familiar sight in Northern Australia of cars abandoned in the desert; from a distance, they look reasonable but, on closer inspection, they are revealed to have rusted and rotted from the inside. Healthcare professionals might also characterize the body as a dot painting, with the cells of the body represented by individual dots, some of which are starting to look different. Other visual means of communication can also be effective, such as showing the patient scans of their tumors, explaining how radiotherapy equipment works using images on tablets, and using pamphlets and flipcharts to illustrate treatments and their side effects.

Repetition and reinforcement help to ground understanding. The cancer communicators in our survey agreed that it is generally better to avoid statistics and medical jargon, and to be led by what the patient wants to know so that they are empowered to make decisions about their treatment. Patients and their families should be provided with advance warning in situations in which a healthcare professional foresees a difficult discussion about sensitive issues or when they need to "break bad news." This can help avoid shock, and will ensure that the patient's supporting family or community members are included in the discussion.

Obtain Support from Those Who Can Assist in Communication

When discussing cancer and cancer treatments with patients for whom English is not a first language, it is

essential that Indigenous interpreters are physically or virtually present, to ensure patient understanding. If a formal interpreter is unavailable, then Aboriginal Liaison Officers, who are very experienced in communication, or any on-site Aboriginal Health Worker may be able to assist. Aboriginal Liaison Officers usually work in hospitals to help with transitions between the community and hospitals. Aboriginal Health Workers usually provide care in community clinics.

Patients are often accompanied by patient escorts (e.g., family member, friend etc.) who may also be able to help interpret for the patient. These escorts often return home to the community with the patient, and may help to explain follow-up care to the patient's family. However, it is always preferable to use professional interpreters rather than escorts or relatives to ensure accuracy of translation. It should be noted that, in small communities, it may be difficult to find an interpreter without kinship ties to a patient, and both male and female interpreters may be needed depending on the gender of the patient and their preference for only discussing their health with someone of the same gender or not discussing these issues with someone to whom they are related.

Engagement with Indigenous interpreters (professional or otherwise) is more than a matter of linguistic translation; it also helps to ensure that cultural sensitivities are integral to the therapeutic conversation. It is also important that the patient's preferences are recognized and that they give their consent for engaging others, such as interpreters or Aboriginal Liaison workers, in their care and treatment.

Consider Culture

An Aboriginal Liaison Officer interviewed for this study provided the important insight that Indigenous peoples tend to live more collectively and are far less individualistic than non-Indigenous Australians. What is best for the community can often outweigh individual priorities. With regard to healthcare, collectivism may manifest as prioritizing a community responsibility, such as sorry business, over attending a cancer treatment appointment. For the patient, this is an appropriate prioritization, even if it leads to a poorer cancer outcome. The importance of being physically and spiritually connected to Country and to family cannot be overstated and not being in Country can, in itself, lead to poor health outcomes. Patients may reject treatment or not complete a full treatment plan if it requires long periods away from Country. Furthermore, a patient may deny a cancer diagnosis to avoid the shame of bringing cancer back to their community.

Patients may wish to incorporate traditional remedies into their treatment and should be given the opportunity to express and do this.

Awareness of the Context of Behavior

Both healthcare professionals and patients may bring to their consultations biases and attitudes based on past experiences, cultural differences, and beliefs. Identifying these requires self-reflection on the part of the healthcare professional. Historical wrongs, such as the Stolen Generation or more recent experiences of discrimination, may result in mistrust and fear [4]. Patients who present with late-stage disease and have poor outcomes reinforce negative attitudes that the Indigenous community may have towards Western medicine. A cancer diagnosis may carry a different significance for the patient and for the healthcare professional. For example, the patient may attribute their diagnosis to unresolved family disputes and may require different or additional remedies to those offered by Western medicine.

Indigenous Australians represent a great variety of languages and belief systems. Health workers must ensure that patients understand what is being communicated to them. Some patients may indicate understanding to avoid discomfort and embarrassment, or to avoid being labelled as ignorant. They may not wish to shame health professionals for poor communication or simply assume that health professionals lack the skills to communicate appropriately.

Failure to attend an appointment may be due to the culturally appropriate prioritizing of community or family responsibilities [5]. In addition, healthcare services may face difficulties following up with patients who have changed phones, live outside urban areas, are transient and of no fixed address, or have left town to avoid matters they do not wish to discuss.

Characteristics of a Good Communicator

From the Indigenous perspective, a good communicator shows respect by deep quiet listening (Dadirri – in the Ngan'gikurunggurr and Ngen'giwumirri languages in the Daly River region of the Northern Territory), being open and still, and letting a story unfold. Ganma (Yolŋu people's concept from Arnhem land in the Northern Territory) is cultural knowledge sharing in which each participant recognizes the combined and individual experiences of the other and mixes these together to form new knowledge [6]. In this context, a good communicator is generally considered to be someone who is personable, honest, person-centered, demonstrates a genuine interest in the other person, and displays genuine empathy. This requires a willingness to engage in personal reflection and self-awareness.

Drawing on the experience of health professionals who communicate about cancer and its treatment to Aboriginal Australians we developed insights into successful strategies for effective communication. These include establishing a

rapport in the appropriate setting, using pictorial illustrations, and utilizing people in the health team who can help the clinician understand the language, the social context, and culture of the patient.

Indigenous People's Understanding of Advance Care Directives

The second study, which is ongoing, explores the issue of communicating end-of-life decision-making with Indigenous patients, with a focus on their understanding of Advance Care Directives. Death and dying are sensitive issues in all cultures and, as part of a larger study investigating whether current advance care planning policy and procedures in Australia meet the needs of vulnerable populations, this study investigates the needs of Indigenous peoples [7]. The study, conducted by Christine Doolan, an Aboriginal woman of Southern Arrente descent, explores the reasons why Indigenous people are less likely to complete Advance Care Directives or End-of-Life Care Plans that support their spiritual, physical, emotional, and cultural wellbeing at the end of life. The research includes interviews and focus groups with Aboriginal communities in South Australia.

The study to date reveals that strategies leading to successful engagement with Indigenous communities begin with the inclusion of Indigenous researchers from institutions respected by the community [personal oral communication, J Elliott, 2023 May]. Each aspect of the project, including recruitment materials, language, and visuals, must be culturally appropriate. Engagement takes time, so flexibility with regard to the time and place of meetings (face-to-face is easier), is essential and reimbursement for the participants' time is desirable.

A common starting point for effective communication is the observation of Indigenous protocols that establish the nature of relationships between individuals and where those individuals come from. Yarning and sharing stories were often vehicles for information-sharing [8]. The interviewer should not make assumptions, but rather ask and listen, creating space for Indigenous interviewees and participants to speak in their own time and space. This can encompass both research methodology and communication with patients about their end-of-life decisions.

Those who wish to engage in sensitive conversations must recognize that Indigenous people are resourceful and compassionate and often put their own needs last. Our own experience has shown that many Indigenous people mistrust the Western medical system and are unlikely to want to die in a hospital. They may even feel shame resulting from years of being blamed for their health issues, despite having limited choices.

To date, we know that end-of-life care involves more than physical care. It also involves healing that is inclusive of Indigenous communities and beliefs, and it may include traditional Indigenous healers (such as Ngangkari healers among the Ngaanyatjarra, Pitjantjatjarra, and Yankunytjatjara peoples of Central Australia).

Decisions about end-of-life care must include family and community members who are trusted to make decisions and to communicate the patient's wishes for their Advance Care Directive. Many Aboriginal people will want to return to Country to die. Those from the Stolen Generation may not know where they have come from, bringing profound sorrow. Christine Doolan's initial interviews highlight the importance of recognizing individual differences and not generalizing or regarding Indigenous people as a homogeneous group (e.g., the needs and preferences of those living in urban settings will likely differ from those living in remote communities).

Unsurprisingly, many of the Aboriginal people involved in this research were unfamiliar with the concept of an Advanced Care Directive or they assumed that it referred to funerals or Wills. The existing Advance Care Directive form or kit is not relatable to Aboriginal people. Therefore, Aboriginal Community Health Workers should be trained to explain advance care planning in ways that are meaningful and effective. However, one research participant summed up the biggest communication issue: "Death is something we don't talk about, our mob, because death most people don't talk about in general.... It's a touchy subject."

From the information gained from this research, Christine Doolan aims to provide evidence to policymakers on how Advance Care Directive procedures could be made relatable to Aboriginal people. The plan is expected to conclude during 2024.

Conclusions

The successful communication of cancer and cancer treatment involves careful attention to language, behavior, and setting, and an understanding of the cultural context in which that information is communicated. This requires input from Indigenous peoples. Techniques such as story-telling, the use of familiar visual metaphors, and creating comfortable and safe environments in which discussions can take place will likely contribute to more effective communication in a variety of settings. However, some communication strategies, and the design of outdoor spaces, artworks, and colors relevant to the Country of the people involved, will need to be tailored to fit with specific regions, cultural groups, and individuals. Careful consideration of cultural appropriateness is particularly important when communicating sensitive issues, such as those at the end of life.

The next step in the first project is to interview Aboriginal patients with cancer to further test the success of communication strategies. The innovative methods of using qualitative social science approaches in working with Indigenous health practitioners and patients with cancer will continue, and these projects will further the engagement with Indigenous researchers. The findings of the project will be used to develop training modules to educate health practitioners and researchers. As more Indigenous researchers are trained, they will conduct their own research into effective communication techniques for Indigenous patients.

There is a paucity of research into Advance Care Directives and Indigenous patients. The initial aim of the study is to use the information collected and possible future consultations with more broadly based Indigenous groups by Indigenous researchers to create advocacy tools so that the research findings can be translated into policies that will provide culturally appropriate opportunities for Indigenous patients to plan their end-of-life care.

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