BREAKING BAD NEWS CONVERSATIONS WITH INDIGENOUS ADULTS

by

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Abstract

Breaking bad news (BBN) is a necessary component of communication in health care. When health care practitioners (HCPs) communicate illnesses of a serious nature with Indigenous people, they often do not do so in a culturally safe way, and this can perpetuate health inequities and catalyze poor health outcomes, which are often linked to Indigenous historical trauma. In this integrative review I sought to analyze and synthesize the published experiences of Indigenous adults from Canada, the United States, New Zealand, and Australia with BBN conversations. I included twelve qualitative studies ranging from 1999 to 2022. I obtained the studies through CINAHL (EBSCO), MEDLINE (OVID), manual reference list screening, and citation tracking on Google Scholar. Themes identified were (a) Indigenous identity, (b) HCP misinterpretation, (c) the meaning of words, (d) truth-telling and the prophetic power of words, (e) indirect communication, and (f) the role of family. The review findings can inform HCPs' understanding of potential communication errors and offer recommendations to improve culturally safe BBN conversations. However, it is important to recognize that although commonalities in experience exist, further research is needed to understand and address the unique experiences of BBN in culturally diverse Indigenous tribes and nations.

Table of Contents

List of Tables

List of Figures

Glossary

Advance care planning: formally documented preferences for future health care.

Biomedical ethics (bioethics): a traditionally Western field of ethics that explores moral, social, and legal issues in health care. Its four principles are non-maleficence (do not cause harm), beneficence (do good, prevent harm), autonomy (respect preferences), and justice (treat cases alike, be fair).

Breaking bad news: when a health care practitioner communicates information about chronic disease, life-altering illness, or injury that leads to a significant change and results in the patient altering their view of the future.

Center good: an Indigenous bioethic whereby obligations and balance are obtained through Indigenous pragmatism, which values interacting with other beings and the environment, plurality of thought, connections to the community, and growth (Mackay, 2022).

Community hui: a Māori meeting called for a specific purpose, such as funerals, weddings, welcoming distinguished visitors, and having a decision-making forum. The purpose can be to share knowledge, experiences, or perspectives within communities. These meetings are often conducted in a *marae*, a traditional meeting place. Community hui can be a component of culturally appropriate Māori research practices.

Cultural competence: when a health care practitioner learns about the patient's cultural customs, a possible side effect is the "othering" of people of that culture because cultural competence is fixated on differences.

Cultural safety: a decolonizing effort based on the HCP's continual reflective self-assessment of their power, privilege, and biases. The patient determines what (encounter) is culturally safe.

Health literacy: Health literacy means patients can access, understand, appraise, and use information and services in ways that promote and maintain good health and well-being.

Hózho: a Navajo term that relates thinking and speaking in the "Beauty Way," it can be a manifestation of hope, and a way of creating and maintaining balance, harmony, beauty and order.

Indigenous historical trauma: trauma rooted in colonization (e.g., conquest, plunder, impoverishment) resulting in population decline and the subsequent subjugation of Indigenous people that has accrued across generations of Indigenous people leading to shared vulnerabilities that undermine contemporary health status.

Nurse practitioners: advanced practice nurses with additional education, the expansion of whose scope allows for autonomous assessment, diagnosis, and management of patients.

Serious illness conversation: recurring conversations about the patient's illness, including its implications, prognosis, treatment options, and care goals.

Virtue ethics: morality is a matter of realizing character traits (virtues) that express being a good person.

Yarn(ing): conversational storytelling used by Aboriginal Australians and Torres Strait Islanders to share, build relationships, and preserve knowledge by passing information from generation to generation. It can be a tool used in culturally appropriate research practices.

Abbreviations

ACP	Advance Care Planning
AI	American Indian
BBN	Breaking Bad News
HBV	Hepatitis B Virus
HCP	Health Care Practitioner
IHT	Indigenous Historical Trauma
NP	Nurse Practitioner
PC	Palliative Care
RCT	Randomized Clinical Trial
SIC	Serious Illness Conversation

Dedication

This project is dedicated to my late grandmother, Violet, and all Indigenous people who have been misunderstood and misinterpreted in a health care encounter.

I respectfully acknowledge that I conducted my research and writing on the unceded lands of the Stó꞉lō people. I am grateful for the teachings I have received from my Elders and family. I am a woman of mixed Stó꞉lō and Western European ancestry, schooled relentlessly in Western biomedical ways of thinking. I am humbled by what this project has taught me—that although being Indigenous shapes how I see and conduct health care, it does not automatically make the care I provide culturally safe.

Breaking Bad News Conversations with Indigenous Adults

Breaking bad news (BBN) from a biomedical perspective occurs when a health care practitioner (HCP) communicates information about chronic disease, life-altering illness, or injury that leads to a significant change and results in the patients' altering their view of the future (Berkley et al., 2018). Although it is a necessary health care activity, the BBN approach does not adequately consider Indigenous persons' unique cultures and experiences. Instead, a Western biomedical perspective is prioritized.

Communicating illnesses of a serious nature to Indigenous people is often not done in a culturally safe way, which can perpetuate health inequities and catalyze poor health outcomes (Beddard-Huber et al., 2021). Indigenous people worldwide experience a disproportionate burden of morbidity and mortality compared to non-Indigenous people. For example, age-standardized mortality rates for First Nations people on reserve in Canada are 1.7 times higher than those of non-Indigenous people (Park, 2021). For those off reserve, it is 1.3 times higher (Park, 2021). Of note, most of these causes of death are secondary to a chronic disease process; examples include heart disease, chronic lower respiratory diseases, and diabetes (Park, 2021).

Communication barriers between Indigenous people and HCPs exacerbate these complex health issues and include miscommunication (Carrese & Rhodes, 2000; Colclough & Brown, 2014; Davies et al., 2014; Garroutte et al., 2006; Hodge et al., 2021; Kaufert et al., 1999; Olver et al., 2022; Rheault et al., 2020), mistrust (Davies et al., 2014; Hodge et al., 2021; Olver et al., 2022; Rheault et al., 2020), decreased health literacy (Beddard-Huber et al., 2021; Davies et al., 2014; Rheault et al., 2020), and differing cultural interpretations of a disease's significance and meaning. Theoretically, a higher burden of disease should translate into better health services for Indigenous peoples, including those geared toward managing illness in a manner congruent with patient values. However, this is not happening, and discriminatory practices are being perpetuated. A thorough exploration of this issue is warranted, and the following research question guides it: How do Indigenous adults experience breaking bad news conversations with an HCP?

Background

Understanding cultural safety in the context of BBN is an important first step in exploring this research question. Further investigation of concepts such as palliative care, advance care planning (ACP), Western and Indigenous bioethics, historical trauma, and the experience of health and colonization will form the foundation of the discussion on BBN with Indigenous adults.

Breaking Bad News: A Biomedical Communication Strategy

Communication is the cornerstone of patient care, and BBN is a necessary part of it. BBN occurs when an HCP shares health information that will alter a patient's expectations for their future, resulting in sustained and typically negative cognitive, behavioural, and emotional responses (Berkey et al., 2018; Jalali et al., 2023). BBN conversations are not limited to palliative diagnoses; they include topics such as chronic disease (e.g., kidney disease), overtly degenerative diseases (e.g., ALS), disease progression, poor prognosis, failure in treatment (e.g., a tumor did not shrink after chemotherapy), and treatment complications (e.g., postoperative infection; Berkey et al., 2018; Jalali et al., 2023). A hallmark of these conversations is that the patient, not the HCP, decides what is considered bad news (Berkey et al., 2018; Jalali et al., 2023). The implication is that when an HCP imparts health care information they view as relatively benign, such as a need to escalate to insulin therapy, the patient may not conceptualize it this way. The news could have a profound and unanticipated impact on the patient, highlighting the need for HCPs to gain a deeper understanding of the cultural safety of BBN conversations.

Many tools have been created to support the BBN process. Most of them have different iterations of a three-stage process—before sharing the news, while sharing the news, and after sharing the news (Jalali et al., 2023). The most well known of BBN tools is the SPIKES Protocol, an oncology-based tool that Baile et al. (2000) developed. SPIKES stands for Setting up, Perception, Invitation, Knowledge, Emotions with Empathy, and Strategy or Summary (Baile et al., 2000; see Table 1). Mahendiran et al. (2023) conducted a systematic review demonstrating that the SPIKES Protocol can "improve clinician confidence and capacity, reduce anxiety, avoid miscommunications, and increase the patient's decision-making engagement" (Mahendiran et al., 2023, p. 1232). Various BBN tools acknowledge the importance of adapting BBN tactics depending on the patient's culture, including the family's request of non-disclosure, and modification of tools and protocols (Beddard-Huber et al., 2021; Clayton et al., 2007; Dunaievska & Chaiuk, 2020; Fahner et al., 2019; Holmes & Illing, 2021). Because of the heavy toll BBN can place on clinicians and patients, clinicians need to be well-versed in initiating the conversation, especially when working with vulnerable populations exposed to many traumas at the hands of the Western biomedical system.

Palliative Care and Associated Important Definitions

The distinctions among BBN, serious illness conversations (SICs), ACP, and palliative care (PC) is an important consideration for this research topic. PC is an evolving concept rife with semantic ambiguity and disagreement. Traditionally, PC was relief of suffering at end of life, with a significant focus on cancer and associated physical pain (Radbruch et al., 2020). It then evolved to focus on life-limiting illness beyond cancer around the time that Baile et al.

(2000) developed BBN. PC is now understood to be "active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life" (Radbruch et al., 2020, p. 1). PC as a care modality does not hasten death, may include disease-modifying therapies, and delineates the importance of psychosocial care (Radbruch et al., 2020).

SICs are broad and recurring conversations about the patient's illness, including its implications, prognosis, treatment options, and care goals (Lakin et al., 2017). Within the literature, SICs are more directly associated with palliative diagnoses and the use of a conversation guide or formal program, for instance, the Serious Illness Care Program. ACP is a formally documented SIC that becomes legally binding (Lakin et al., 2017)—for example, an advance directive. It is a communication process that articulates preferences for future health care and can be revisited as health status changes (Fahner et al., 2019). ACP can occur before any known life-limiting illness or follow a diagnosis and disease progression.

Relationship of Palliative Care, Serious Illness Conversations, and Advance Care Planning to Breaking Bad News

BBN does not just happen when the HCP reveals a terminal diagnosis. Deciding what news is "bad" is the patient's decision and therefore is not limited to palliative diagnoses. BBN occurs within the greater context of SICs. ACP is done in the context of current or planning for future BBN and is therefore also relevant to the research question.

Preferred terminology regarding BBN is constantly changing. Newer terms include *serious illness communication* (Lakin et al., 2017), *sharing life-altering information*, and *discussing* or *breaking serious news* (Harman & Arnold, 2024). Some authors prefer the latter term over BBN because it mitigates the HCP's ability to define something as bad (Harman &

Arnold, 2024). Although terminology is important, it is less important than the patient experience of these conversations.

Indigenous and Western Bioethics: Autonomy versus Center Good

Bioethics underpins and shapes the whole patient and HCP experience of health care and BBN discussion. Therefore, it is an important consideration when conducting a review of the topic. This requires defining bioethics; knowing how Indigenous and Western bioethics differ; and understanding how these varying approaches affect values, decision-making, and the patient experience.

Bioethics comprises the values and principles that guide philosophical, legal, and ethical issues in health and medical care (Fisher et al., 2018). The Western health care system runs on Western ethical approaches, which do not always fit with Indigenous ones. This means that Western ways of thinking and doing in health care are taught to HCPs, prioritized, and often implemented without question. A brief explanation of Western bioethics helps demonstrate this.

Western Bioethics: Issues of Autonomy and Informed Consent

Moral reasoning and its outcome in a Western approach to health care typically relate to one of the four biomedical ethical principles: non-maleficence (do not cause harm), beneficence (do good, prevent harm), autonomy (respect preferences), and justice (treat cases alike, be fair; Fisher et al., 2018). These ethical principles compete; for example, strong paternalism occurs when perceived beneficence is prioritized over autonomy (Fisher et al., 2018). All ethical decisions are unique. Each decision requires an HCP's assessment. "Moral" decisions are based on these principles. They are supplemented by non-moral facts of the specific situation including clinical (e.g. diagnosis, prognosis, treatment, risks, benefits); quality of life and death; preferences of the relevant parties (e.g. patient, family, HCP); and contextual features such as financial cost and laws (Fisher et al., 2018). The patient's individuality is prioritized, and these moral and non-moral facts must be weighed to make the right decision.

Informed consent is an important consideration in biomedical all BBN conversations. To obtain informed consent, the HCP shares the risks, benefits, and alternatives of a given procedure or intervention with the patient (Fisher et al., 2018). It is an exercise of autonomy typically focused on the patient's agreeing to or refusing a proposed treatment plan, often culminating in a signed legal document (Fisher et al., 2018). However, informed consent goes beyond treatment decisions.

A requisite part of informed consent is that meaningful information about the health care situation is shared with the patient, not withheld; typically, this includes sharing life-altering diagnoses and their adverse implications. Rudnick (2002) explored how this information sharing is not so simple, in that informed consent to diagnosis and treatment differs from informed consent to breaking or waiving bad news. Rudnick gave the example of a patient with a family history of Huntington's disease (2002). The patient could choose to be tested (consent to diagnosis) but refused to be informed of the results (no consent to BBN; Rudnick, 2002). A patient, therefore, can consent to have information withheld.

Rudnick proposed a solution to avoid implying bad news (2002). If the HCP asks the patient whether they want the Huntington test results after the tests are drawn, it could imply that the news is bad. Rudnick recommended clarifying patient values and preferences prior to conducting tests to ascertain if they want to know bad news should it occur (2002). This illustrates how HCPs can be flexible with their approach to care to meet patients' needs and obligations of informed consent. What is less clear is how this can be addressed in the context of BBN with Indigenous adults.

Indigenous Bioethics: A Different Way of Conceptualizing Health Care

Indigenous bioethics are rooted in a different way of thinking and being, compared to Western bioethics. MacKay (2022) argued that the concept of a center good is central to Indigenous bioethics. That is, obligations and balance are obtained through "Indigenous pragmatism which values *interacting* with other beings and the environment, *plurality* of thought, connections to the *community*, and *growth*" (p. 1). An inherent outcome is that an Indigenous patient may view autonomy not as an individual choice but rather as a fundamental interaction between oneself and one's community (MacKay, 2022). This contrasts with the biomedical model of individualism, autonomy, and body (MacKay, 2022), whereby a reductionist approach is used to determine which biological mechanical function is malfunctioning (Ahenakew, 2011). This is the system in which HCPs, including Indigenous ones, study and practice. The biomedical model divides the patient's mind, body, spirit, and emotion into its parts (Ahenakew, 2011). An interpretation is that the diagnosis process could fracture the patient (Ahenakew, 2011) from the *center good*. The result is further understanding that bioethics, ways of knowing, and the laws and norms of HCPs usually follow Western biomedicine and therefore influence how BBN conversations are conducted.

Indigenous Bioethics: Treated as Just a Helpful Secondary Perspective

Indigenous ways of knowing are rarely integrated into biomedical ethics, and even in these rare cases, are often perceived as helpful secondary perspectives (Kotalik & Martin, 2016; MacKay, 2022). An example helps explain this. The Ojibway have a traditional story known as the Gifts of the Seven Grandfathers that is thought to parallel Western virtue ethics (Kotalik & Martin, 2016). In the story, the Seven Grandfathers only found one helper, an uncorrupted baby, who could teach humans how to live better. The baby journeys to see all Creation, grows up, and is given a gift by each Grandfather with a lesson (wisdom, love, respect, bravery, honesty, humility, and truth), which he brings back to his village in his old age (Kotalik & Martin, 2016). Virtue ethics, as understood by a biomedical source, are psychological states such as fair-mindedness and patience that play a role in making “good” HCPs but are less useful in health care decision-making (Fisher et al., 2018). This means that HCPs’ personal virtues are not as important as their objective practice and decisions. Kotalik and Martin (2016) stated that labeling the Gifts as a simple variant of virtue ethics is inappropriate. Indigenous bioethics recognizes these stories as highly important and as providing comprehensive moral guidance for health care decision-making (Kotalik & Martin, 2016). Furthermore, the personal values of an HCP shape how much they are trusted. Health care, including BBN conversations, becomes problematic for Indigenous people if HCPs misunderstand Indigenous way of knowing and see them only as a secondary consideration to their health care journey.

Blood Memory: Indigenous Historical Trauma and Pathologizing

Historical trauma is a construct that can help explain the experience Indigenous people have of health care at both the population and individual level. This trauma is present and studied in those from different ethnicities, including descendants of the Jewish Holocaust, African Americans, and Indigenous peoples around the world (Gone et al., 2019). Indigenous historical trauma (IHT), specifically, is

> universally characterized as originating in the brutal processes of colonization (e.g., conquest, plunder, impoverishment), which resulted in population decline and subsequent subjugation of Indigenous peoples . . . [which] accrues across generations of Indigenous people leading to shared vulnerabilities that undermine contemporary health status. (Gone et al., 2019, p. 21)

Furthermore, IHT shapes the Indigenous person's perceptions of disease, healing, and subsequent health behaviours (Joo-Castro & Emerson, 2020). Reaction to and experience of BBN is no exception to this, especially considering how traumatic hearing bad news may be. Some researchers think that intergenerational transmission of IHT occurs through social or epigenetic pathways, with the former more heavily studied (Joo-Castro & Emerson, 2020). Social pathway IHT occurs when an Indigenous person hears stories of trauma and feels the experience themselves or hears nothing about it and imagines the worst (Joo-Castro & Emerson, 2020). Social pathway transmission can also occur through maladaptive parenting practices rooted in abuse or neglect, which can be catalyzed by surviving the residential school system (Joo-Castro & Emerson, 2020). Tied with this social view is the notion that IHT should be conceptualized metaphorically, a way of making meaning of the continued collective impact of colonization and assimilation (Gone et al., 2019). In other words, it is a way to understand and rationalize the experience of vicariously experienced trauma. Perhaps it is also an avenue for understanding that trauma imparted through an ancestor's BBN experience may impact the modern patient and family.

The epigenetic pathway theory proposes that IHT is a literal scientific construct in which extreme and prolonged stress can influence gene expression or suppression in offspring, creating vulnerability to illness (Gone et al., 2019; Joo-Castro & Emerson, 2020). Rogers-LaVanne et al. (2022) studied Alaskan Natives and found a connection between historical loss and altered DNA methylation patterns in various genes controlling functions such as the immune system, homeostasis, and metabolism. Even though there is no academic literature exploring a directional relationship between IHT and BBN, it is important to consider a possible connection. Regardless of the theory implemented, IHT is in the background of their health care experience.

An unfortunate side effect of acknowledging IHT is that it may pathologize the lives of entire communities, whereby "the 'traumatized Aboriginal' is constructed by academics, practitioners, and politicians" (Ahenakew, 2011, p. 22). This means that by learning about ITH to promote health, further trauma is paradoxically created. Pathologizing the lives of Indigenous people has another consequence. Indigenous persons may experience internalized racism—a form of cognitive imperialism—whereby they hear and believe negative messages about their abilities and intrinsic worth stemming from medical and social sciences, resulting in helplessness and hopelessness (Ahenakew, 2011). BBN practices, therefore, must carefully navigate this backdrop of traumatizing and pathologizing. The HCP must remember and espouse the capacity of Indigenous persons, even when sharing news that may be perceived as bad.

Complexities of Health and Disease During Colonization: Seeding Distrust

Health and disease have an intricate relationship with the colonization of Indigenous populations and the manifestation of modern-day trauma and distrust (Canadian Medical Association, 2024; Robson, 2018; Smallwood et al., 2020). Canada, the United States, New Zealand, and Australia are four countries that share similar colonial pasts under the British Empire, including the treatment of Indigenous populations. Broadly speaking, "civilizing the Indian" and genocide were the modus operandi of colonization (Carlson & Stó:lō Heritage Trust, 1997; Truth and Reconciliation Commission of Canada [TRCC], 2015). Only within the last few decades have these atrocities been acknowledged, yet not ameliorated, and the IHT it has generated across the globe is only now starting to be understood and deemed a priority (TRCC, 2015).

Among the first wounds inflicted by settlers were mass epidemics such as smallpox, which resulted from contact and indirect contact through Indigenous trade routes, wiped out large populations, and weakened Indigenous defences (Carlson & Stó:lō Heritage Trust, 1997; Lange, 2018; National Museum Australia, 2022). The outbreak soon became intentional. Records exist of a 1783 effort to use smallpox near what is now known as the US state of Delaware. British Army Colonel Henry Bouquet suggested, "I will try to inoculate the Indians by means of blankets that may fall in their hands taking care however not to get the disease myself. As it is a pity to pose good men against them . . . [to] effectively extirpate or remove that Vermine. H.B." (Bouquet, 1763, as cited in Finzsch, 2008, p. 223). This specific letter was followed by a subsequent letter saying two blankets and a handkerchief from a smallpox hospital had been given, and there had been an outbreak (Finzsch, 2008).

Disease also ran rampant because of forced large-scale land confiscations, resulting in detrimental changes in housing density, water supply, sanitation, diet, and cultural land ties for the Indigenous people of Canada (Truth and Reconciliation Commission of Canada, 2015), the United States, Australia (Griffiths et al., 2016), and New Zealand (Lange, 2018; Thom & Grimes, 2022).

Western biomedical health care and scientific advancement were also vectors of these historical wounds, setting the stage for distrust of the health care system and possibly shaping the experience of BBN conversations. Indigenous men, women, and children were victims of forced medical experimentation and procedures in the 20th century. Indigenous Canadians were the recipients of forced sterilization, childhood nutritional experiments resulting in malnourishment, X-ray pilot studies, experimental tuberculosis vaccines, and perhaps lobectomies (Canadian Medical Association, 2024). American Indians were also subject to forced sterilization (Pacheco et al., 2013), and experimental trachoma treatments were performed on boarding school students (Dawson, 1967). Radioactive iodine was tested on the thyroid tissue of Alaskan Americans without proper consent or medical follow-up (Advisory Committee on Human Radiation Experiments, 1994). Aboriginal Australian children, albeit not proven, were subject to experimental Hansen's disease treatments against their will, and adults with venereal disease were forced into isolation on a remote island (Robson, 2018). All these experiences create a backdrop of distrust, generate further IHT, and shape the experience of BBN conversations.

Cultural Safety: A Brief Overview

Cultural safety is central to care and communication with Indigenous patients. In light of the identified issues, I strongly felt that an elaboration of cultural safety was essential to include when exploring this topic. My rationale is that it is essential to avoid perpetuating colonial ideas of Indigenous research and instead aim to present the research in a way that may prompt the reader to conduct a self-assessment before engaging in BBN conversations.

The patient's experience of a health care encounter as secure and respectful determines cultural safety (Curtis et al., 2019). To facilitate cultural safety, HCPs need to decolonize their care provision by continual reflective self-assessment of their power, privilege, and biases (2019). It is imperative that cultural safety is not confused with cultural competence. The latter is focused merely on the HCP's learning about the patient's cultural customs, with the possible side effect of "othering" them (Curtis et al., 2019), resulting in further marginalization. In this review I intend to provide knowledge that may trigger a self-assessment upon engaging in BBN discussions, rather than to offer generalized cultural customs.

Methods

Study Design

The purpose of this integrative review is to gather and synthesize evidence articulating the experiences that Indigenous adults have had with BBN conversations. A systematic approach was used, guided by an integrative review methodology (Whittemore & Knafl, 2005) and by modified usage of the 16-point PRISMA-S Checklist for systematic reviews (Rethlefsen et al., 2021; see Table 2). Both resources ensured that each component of the literature search was complete and therefore reproducible and that all relevant data were captured, not just sources supporting one perspective.

Original Search Summary

A comprehensive search was designed and conducted. The original search strategy began with a brief Google Scholar search and was followed by a preliminary search of CINAHL (EBSCO) and MEDLINE (OVID). Search terms for both databases fit into one of three themes: (a) communication; (b) BBN, serious illness, or palliative care; and (c) Indigenous people, used with appropriate Boolean operators, truncation, keywords, subject headings, and MeSH terms (see Table 3). Indigenous persons filters created by Campbell et al. (2014) were used to increase recall.

Refined Search Strategy: A Second Attempt

The serious illness conversations that were acquired by the search appeared to be more fixated on communicating a terminal prognosis, for example, metastatic cancer diagnoses. Subsequently, the research question and search terms were adjusted to include more comprehensive terminology such as breaking bad news. The CINAHL (EBSCO) and MEDLINE (OVID) searches were re-run, including these new terms. No date limit was set based on the presumption that Indigenous wisdom, even in academic literature, would still answer the research question, regardless of age. Manual reference list screening and citation tracking on Google Scholar were done for all included studies.

Inclusion and Exclusion Criteria

Inclusion criteria were Indigenous populations in Canada, the United States, New Zealand, and Australia, or health care providers working with these populations. Table 3 shows the combined and incorporated terms. Exclusion criteria included the following: not an Indigenous patient population, focused on end of life (i.e., actively dying), caregivers only, bereavement, documentation, symptom or disease management, pediatrics, and a lack of rigour (i.e., an opinion piece). Studies were tagged in Covidence software (2025) with the rationale for exclusion.

Search Results

Zotero (2025) software was used to store the records, and a PRISMA flow diagram (Rethlefsen et al., 2021) depicted how records were managed (see Figure 1). Two thousand sixty-three records were obtained. The title of each study was skimmed in Zotero, and 1,361 records were removed for being grossly off-topic, for example, in India, conference notes, or suicide. The remaining results were uploaded to Covidence (2025). Covidence was used to manage and screen 290 studies, and 37 duplicates were removed. The abstracts and titles of all 253 studies were read, and studies were tagged with (a) yes, (b) maybe, (c) no, or (d) background based on the inclusion and exclusion criteria. All yes, maybe, and background studies were reviewed again to ensure accurate tagging. Fifteen studies were tagged as yes and progressed to the analysis step.

All studies were read once, and first impressions were written down. Upon further analysis, three studies were removed because they did not meet the inclusion criteria. The 412 references found in those original 12 studies were screened and tracked directly on the reference list. No new studies were found.

Analysis

Studies were reread and critically appraised using the Critical Appraisal Skills Programme tool (Critical Appraisal Skills Programme, 2018). Subsequently, three tables (Tables 4, 5, and 6) were created to capture data analysis. Data analysis included research methodologies, results, strengths and weaknesses, rigour, and data saturation (Whittemore & Knafl, 2005). Because Indigenous research methodology was a priority, Indigenous specific data points were collected: Nation or tribe, identity of participants, Indigenous authorship and involvement in research; community approval; member checking; adherence to ownership, control, access, and possession (OCAP) principles (First Nations Information Governance Centre, n.d.; Konczi & Bill, 2024); and cultural concepts and practices. Themes were extrapolated, and their relevance to the population, intervention, and outcome (PIO) question was recorded.

Findings

Analysis of the 12 studies demonstrated how being Indigenous shaped the meaning of BBN and points to an underlying difference in bioethics. Themes include the following: the nuances of identity, miscommunication, the underlying meaning of words, and the role of family when BBN to Indigenous adults.

Twelve studies were obtained from distinct Indigenous Nations from the four aforementioned countries. Two studies were from Canada (Beddard-Huber et al., 2021; Kaufert et al., 1999); six from the United States (Carrese & Rhodes, 2000; Colclough & Brown, 2014, 2019; Garroutte et al., 2006; Hodge et al., 2021; Lille et al., 2020); three from Australia (Davies et al., 2014; Olver et al., 2022; Rheault et al., 2020); and one from New Zealand (Cassim et al., 2021). Publication dates ranged from 1999 to 2022; two of the earliest publications were seminal studies that laid the groundwork for Indigenous adults' experiences with BBN conversations (Carrese & Rhodes, 2000; Kaufert et al., 1999).

The earlier studies by Carrese and Rhodes (2000) and Kaufert et al. (1999) appeared to implement more ethnographic approaches than later studies did. Carrese and Rhodes (2000) involved Indigenous people in the research, albeit not as partners. Findings were presented to and feedback solicited from members of the Navajo community where they conducted the study, but community members were not involved in the research design or authorship (Carrese & Rhodes, 2000). An anthropologist of unknown ethnic identity with expertise in Navajo culture served in an advisory position (Carrese & Rhodes, 2000), thereby highlighting the value of academic wisdom over Indigenous ways of knowing, for example, wisdom from a respected Elder. Kaufert et al. (1999) did not involve Cree or Ojibway people in any part of the research process. A possible explanation is that these studies were conducted during a time when Indigenous wisdom was something to be studied but not valued, before an understanding of OCAP principles had been disseminated. In contrast, recent studies appear more likely to stem from a community-based participatory approach that attempts to follow OCAP principles (Cassim et al.; Rheault et al., 2020).

Broadly speaking, the studies fit into one of four categories associated with BBN: lived experience with illness (Davies et al., 2014; Hodge et al., 2021; Olver et al., 2022; Rheault et al., 2020); end-of-life communication (Colclough & Brown, 2014, 2019; Kaufert et al., 1999); modification of a health communication tool (Beddard-Huber et al., 2021; Lille et al., 2020); or health communication as a broader entity (Carrese & Rhodes, 2000; Cassim et al., 2021; Garroutte et al., 2006). Only three of the studies were focused on cancer (Cassim et al., 2021; Hodge et al., 2021; Olver et al., 2022)—a surprise considering how heavily cancer diagnoses are associated with BBN.

Themes that emerged across the studies include Indigenous identity, HCP misinterpretation, the meaning of words, truth-telling and the prophetic power of words, indirect communication, and the role of family.

Considering Uniqueness: Indigenous Identity

Several researchers found that a patient's identity can shape their experience of BBN conversations and preferred communication strategies. Some Indigenous patients may not hold traditional cultural beliefs, influencing a possible preference for a biomedical approach to health care and medical communication, including BBN conversations (Carrese & Rhodes, 2000; Colclough & Brown, 2019; Garroutte et al., 2006; Lillie et al., 2020). Other topics included the influence of identity on communication patterns, the nuances of dual identity, and the modifications made by HCPs in their approach to BBN based on patient identity.

Garroutte et al. (2006) investigated in their mixed-method study whether communication patterns of HCPs and Cherokee patients varied depending on the level of identification with American Indian (AI) and White American identity by coding utterances of audio-recorded patient–primary care provider appointments and then categorizing and comparing instances of patient talk (Garroutte et al., 2006; see Table 7). The authors used two validated self-rated ethnic identity indices to assess AI and White American identity. A strength of their approach was the assessment of relevant covariates, for example, the number of prior visits to those HCPs. They found that Cherokee patients in their study had a mean rating of 1.4 out of 3.0 on the AI identity index and 2.5 out of 3.0 on the White American identity index, with a strong caveat—these identities are not mutually exclusive. Furthermore, Garroutte et al. concluded that identity shapes communication patterns; Indigenous adults who more strongly identified as AI produced more instances of positive talk in the clinical encounter. A possible consideration is that those who agreed to participate may have had a stronger baseline of White American identity, thereby skewing the averages present in the larger population.

Carrese and Rhodes (2000) conducted a sentinel study addressing BBN with Indigenous adults. In their focused ethnography, interviews were conducted with Indigenous patients (*n* = 20), HCPs (*n* = 6), and traditional healers (*n* = 6) to explore culturally competent strategies that HCPs can use for discussing negative (health) information with Navajo patients. They explored the cultural norm of not talking about negative health information and, in their discussion section, elaborated extensively on intracultural variation in individuals' values and behaviours. The authors' final suggestion was to ensure the thoughtful and individualized application of the BBN approach (Carrese & Rhodes, 2000).

Lillie et al. (2020) conducted a mixed-methods design and community-based participatory action research approach to adapt an existing ACP tool to make it more acceptable to AI and Alaskan Natives. Study participants were drawn from two Indigenous health care organizations in Alaska and New Mexico, providing care to 250+ tribes. Like Carrese and Rhodes (2000) and Garroutte et al. (2006), Lillie et al.'s (2020) study included Indigenous patients and HCPs. Lillie et al. (2020) also included Indigenous caregivers, administrators, and non-Indigenous HCPs. These varying perspectives help contextualize and contrast experiences. However, unlike Carrese and Rhodes and Garroutte et al., the information elucidated from Indigenous patients in Lillie et al. was not distinguished from data gathered from HCPs. This makes it difficult to distinguish what the Indigenous patients experienced from what the HCPs recommended. The authors found that cultural adaptation of ACP is necessary because culture influences health care choices. Specific recommendations were to limit jargon to increase understandability; making space for the patient to identify who they want involved in their ACP conversation (e.g., family or specific health care workers); and inquiring more about the influence of culture on their life, versus asking only about religion and spirituality (Lillie et al., 2020).

In their community-based participatory research study and mixed-methods design, Colclough and Brown (2019) sought to explore a perception shift, whether it is culturally appropriate, and whether there is readiness to discuss end-of-life in a Blackfeet community. The weakness of this study was its purpose: to help advance the community hospice project. The primary investigator did data analysis alone to hasten publication, and there was potential for bias—reporting results that supported the creation of the project. Strengths included the fact that the researchers had worked with this community for 12 years and had longitudinally researched similar topics, thereby increasing credibility. Another strength was that the community approached the authors to address this research question. Ten recognized Elders were interviewed and 102 adults surveyed. Multiple Elders discussed the complexities of living in two worlds, White and Indian. Some Elders expressed concern about how death and decisions surrounding end of life were becoming individual choices and causing imbalance, because “an attitude change from ‘we’ to ‘I’ does not allow time necessary for ceremonies and recognition of death” (2019, p. 286). The recommendation from the authors based on this finding was to maintain a flexible approach toward the patient and family.

Health Care Practitioner Assumptions: The Root of Miscommunication

Several researchers reported a complex relationship between identity and miscommunication, including topics such as misinterpreting positivity, silence, and shared decision-making. A unique finding from Garroutte et al. (2006) was that patients who identified more as AI produced more utterances of positive talk during a clinical encounter. This created the risk of the HCP falsely interpreting positivity as comprehension, lack of distress, and satisfaction with care (Garroutte et al., 2006). Furthermore, the authors concluded from their findings that these patients may be at risk of passive medical relationships and therefore may not correct an HCP’s inaccurate interpretations.

Hodge et al. (2021) conducted a grounded theory study designed to inform a randomized clinical trial (RCT) on cancer pain in Indigenous adults, its management, and associated cultural constructs. They conducted focus groups with 132 Indigenous cancer survivors from five reservations in the Southwestern United States with the intent of elucidating patient experiences since diagnosis, including cancer-related taboos and cultural barriers. The authors found that HCPs often misconstrue silence as denial and disengagement in care, yet to Indigenous patients, it was a complex way to both maintain harmony and a reaction to historical trauma. Silence was a means of conveying respect by not complaining or questioning the diagnosis, a means of communicating unity or dissent, and a way to keep things light—a presumed culture-bound response to hardship (Hodge et al., 2021). Furthermore, this silence may have stemmed from the patient's reluctance to discuss cancer diagnosis, treatment, and complications even with the HCP, especially if they believed that it was difficult to treat (Hodge et al., 2021). The author suggested that this silence is possibly one reason why many AI cancer survivors were less likely to engage in early treatment. This study's strength included how it tied the findings to the bigger picture of historical trauma stemming from colonization and the large number of participants. One consideration is that the author aimed to inform an RCT, which may have influenced the findings' interpretation and analysis.

Rheault et al. (2021) conducted a qualitative descriptive study of remote residing Kalkadoon adults in Australia diagnosed with at least one chronic disease by conducting open-ended yarning interviews, an Indigenous way of storytelling adapted to inform research. The authors had significant Indigenous involvement throughout the research project, including intentional Indigenous research methodology (yarning); community consultation before commencing research; and Aboriginal health worker involvement in recruitment, study design, and review of findings. They also acknowledged their positionality as non-Indigenous investigators, and data saturation was reached. All 20 study participants, without prompting, elaborated in detail on the confusion, shame, ambivalence, disempowerment, and lack of trust that followed the HCPs' use of medical jargon. Furthermore, Rheault et al. (2021) found that many participants felt unsafe or unable to ask questions about their health care. The authors concluded that these experiences resulted in the participants' being shy and not articulating their lack of understanding. A recommendation from these findings is that clinicians should not view this as an issue of patient incapacity, but rather a failure of the health care system and even clinicians, who expect patients to adapt. Instead, the authors stated that clinicians need to shift from presuming the incapacity of their patients to acknowledging that health care must be adapted to the patient's unique health beliefs.

Colclough and Brown (2014) conducted another study, this time implementing a grounded theory and a community-based participatory research approach to identify Blackfeet values and contributing factors that influence end-of-life decision-making. Open-ended face-to-face interviews were conducted with Indigenous patients, family members, HCPs, and one non-Indigenous HCP. Tribe members were involved in the research design, study questions were pilot tested, data saturation was reached, and tribal members were involved in data analysis. Furthermore, four presentations were made to the tribal council and community to provide updates on study progress and obtain feedback to ensure accuracy of findings. As with their later work in 2019, Colclough and Brown aimed to provide evidence supporting a hospice's creation, which may have impacted the discussion and findings.

Colclough and Brown (2014) found that HCPs, even Indigenous ones, thought they were supporting patients and families in making autonomous decisions. In contrast, patients and families believed the physicians made the decisions—and the diagnosis and treatment were just "given" to them. The authors found that the perception of "diagnoses given" and subsequent actions was rooted in the nuances of informed consent, the lack thereof, and the cultural component of not questioning authority. A possible explanation was that the Indigenous bioethics value of medicine as the "power within all things" may have shaped patients' perceptions of BBN and receiving a diagnosis as unquestionable truths (Colclough & Brown, 2014, p. 509). One recommendation from the authors was to focus on the patient's and family's personal and emotional well-being as a platform to build genuine and trusting relationships, from which belief in autonomy, true informed consent, and shared decision-making could emerge.

Findings in Davies et al. (2014) complemented Colclough and Brown (2014). In a participatory action research project with the Yolŋu people of Australia, Davies et al. (2014) sought to explore the knowledge, perceptions, and experiences of remote dwelling Indigenous adults and their HCPs relating to hepatitis B virus (HBV) infection to create a culturally appropriate education tool. The methods section was detailed and included the interview guide and information about member checking. Member checking involved clarifying the cultural context of terms used and sharing the findings with participants. The authors found that non-Indigenous HCPs overestimated the depth of shared understanding, whereas patients thought their HCP was hiding information from them. The authors also found that the root of this misunderstanding was a lack of shared understanding of the meaning of words, not translation issues. The only recommendation from the authors was to improve health literacy by developing a culturally appropriate education tool.

The Meaning of Words: Diagnoses and Analogies Mean Something Else

The meaning of words was a theme in Colclough and Brown (2014), Davies et al. (2014), and Olver et al. (2022). Colclough and Brown (2014) found that in oral traditions, "words based on their perceived experience carry higher value than scientific evidence" (p. 508). The authors recalled an example of a diabetic patient who received a leg amputation just after starting insulin and how a relative misinterpreted insulin as the cause.

Olver et al. (2022) interviewed Indigenous and non-Indigenous HCPs, hoping to ascertain which strategies were successful in helping communicate cancer and its treatment with

Aboriginal Australians and Torres Strait Islanders. They found that Indigenous patients may know the medical implications of a word such as *cancer*—for example, that it is life-threatening—but in their culture, it means something else, such as shame. The study's premise and approach were problematic, despite having one Indigenous author. Olver et al. sought to define successful communication strategies based on HCP experience only, without confirming the results with the local Indigenous population.

Davies et al. (2014) articulated another example of words meaning different things. The authors found that HCPs used the word "silent" to communicate chronic HBV with a high viral load but limited liver damage; however, patients interpreted "silent" as sorcery. The authors also found that non-Indigenous HCPs thought it was appropriate to use an analogy of crocodiles to explain how chronic HBV can lie dormant and then attack. However, that analogy was deemed inappropriate—it was interpreted to mean that hunted animals could give people HBV. Davies et al. (2014) then discussed how misinterpretation, health beliefs, and health literacy have a complex relationship and why building shared understanding is essential. The only recommendation given by the authors was to improve health literacy by developing and using an education tool grounded in Yolŋu culture and language.

The Power and Prophecy of Words

Multiple researchers mentioned the power of hope and the effect of positive and negative words in the context of BBN. Hope is also important when it comes to the meaning of words. Hope is a familiar concept across mainstream BBN literature, often tempered with the notion of not creating false hope but assessing and promoting psychosocial well-being, that is, being at peace (Clayton et al., 2007; Fahner et al., 2019). Hope for Navajo patients relates to hózho, thinking and speaking in the "Beauty Way," and the active role of HCPs should be to communicate hope and positivity and know there is always something to be done (Carrese & Rhodes, 2000).

Cassim et al. (2021) found that hope was the "how" of communication. Hope was more than just physical health; it encompassed spiritual health and connection to nature. Furthermore, hope required the HCP to provide options when BBN to maintain open-ended hopefulness. The author recommended maintaining hope by promoting holistic, natural, spiritual, and physical wellness while also conveying truth with support and care.

Garroutte et al. (2006) proposed that the higher frequency of positive talk in AIs may maintain the harmony ethic and support the belief that words are powerful enough to shape physical outcomes. Kaufert et al. (1999) conducted a qualitative analysis of their 1990 ethnography; they reanalyzed two patient encounters with First Nations interpreter involvement in truth-telling and negotiating disparate values for guiding end-of-life decision-making in a Winnipeg hospital. One of the encounters was with a 25-year-old Ojibway man dying from AIDS, the other was with a 74-year-old Cree woman dying from complications of a foot ischemia surgery. The authors found that truth-telling was believed to shorten the lives of terminally ill patients and that communication needs to be balanced and convey hope. Considerations are the age of the study, the time gap between research and analysis, the fact that the discussion section integrated findings from the original study's ten remaining ethnography cases, and the lack of elaboration on codes or themes.

Researchers in multiple studies discussed appropriate ways to mitigate the impact of BBN. Carrese and Rhodes (2000) explored the power of words in traditional Navajo culture and articulated that reviewing the story of a patient's illness is an appropriate method of BBN. Furthermore, both Carrese and Rhodes (2000) and Kaufert et al. (1999) suggested that an HCP who has developed a trusting relationship with the patient could state that no harm is intended before BBN. A unique finding from Colclough and Brown (2019) was progressive acceptance of discussing negative information, which was in the context of a longstanding relationship with the community and efforts to promote health and death literacy. The authors conducted research with the same Indigenous tribe for over a decade, which may have influenced this finding.

Indirect Communication: Discrepancy and the Role of Family

Multiple researchers found that family plays a vital role in BBN. Kaufert et al. (1999) found that death and illness do not have to be directly referenced, and sometimes a family member should communicate the bad news to the patient. Cassim et al. (2021) echoed something similar. The authors used a kaupapa Māori approach to explore the experience and ethical implications of Māori adults receiving bad news about lung cancer. Community hui and interviews included patients and family members from the four communities who co-designed the study. Strengths were the level of community engagement, the comparison of the findings to the general population, good use of participant quotes, and the open-endedness of the hui, which captured participants' broader experiences with illness and BBN. The authors found that the whānau (family) act as mediators, meaning they should receive and communicate the bad news to the patient to mitigate trauma and maintain the ill person's spirit, soul, and dignity. The authors also found that the patient's health is deeply connected to the health of the whānau. Interpreting the findings of this study was difficult because the text did not include enough details about the results.

An interesting juxtaposition involved information sharing with families. Some researchers mentioned the importance of including the family in the BBN conversation and collective decision-making (Beddard-Huber et al., 2021; Colclough & Brown, 2014; Olver et al.,

2022) and of seeing the family as a "unit" with the patient and possibly deferring decision-making to a respected person such as an Elder (Carrese & Rhodes, 2000; Cassim et al., 2021). However, other researchers spoke about patients wanting to hide BBN conversations and health information generally from their families because of the shame associated with their condition (Kaufert et al., 1999), or as a trauma-induced response of not wanting to feel like a burden (Hodge et al., 2021). Lille et al. (2020) looked at this from a solutions-based perspective; they found it best practice to ask patients who they want involved in ACP communication and to have the HCP reflect on the fact that health care decisions sometimes will be a collective action.

Beddard-Huber et al. (2021) conducted a quality improvement project involving nurses working for an Indigenous health authority and two First Nations communities in British Columbia to ascertain the cultural safety of, and then adapt, a serious illness conversation guide. The authors conducted two sharing circles of nurse participants and intentionally chose not to assess whether they identified as Indigenous—a problematic approach considering the nurse participants articulated what was culturally unsafe about the guide. The authors found that most nurses believed initiating a one-to-one conversation with the patient was culturally unsafe and that family was needed. Subsequently, the authors presented the nurses' recommended adaptations to two different First Nation communities, validating most of their findings. Key relevant findings were the importance of storytelling while BBN and confirmation that families generally should be included in the BBN conversation. The authors specifically underscored how building a trusting relationship, minimizing power imbalances, and promoting health literacy are the foundations for using a serious illness conversation guide.

Discussion

This is the first known integrative review to analyze and synthesize Indigenous adults' experiences of BBN conversations with an HCP. The most prevalent theme that emerged from this review's findings is that BBN is shaped by patient and family identity and there is complex meaning behind the words spoken by HCPs.

Identity and Bioethics

Identity is not ethnicity; Indigenous cultural and Western biomedical practices uniquely influence a patient's ideal approach to BBN. Garroutte et al. (2006) found that overall, Cherokee patients and the HCPs participating in their study identified more as White American than Indigenous and that these identities are not mutually exclusive. Correlated to this finding is the concept of two-eyed seeing created by Mi'kmaw Elders Albert and Murdena Marshall: simultaneously seeing and acting with Indigenous and Western biomedical ways of knowing (Bartlett et al., 2012; Jeffery et al., 2021). A dual identity could mean a dual understanding of health and illness, resulting in unique preferences for how culturally safe BBN conversations are conducted. This dual identity poses a challenge for NPs: How does the NP in primary care know the identity and preferences of the patient sitting in front of them?

The root of this challenge is the contention between biomedical and Indigenous ways of knowing and their manifestations in health care practices. The practices of direct versus indirect communication (Cassim et al., 2021; Kaufert et al., 1999); maintaining positivity (Carrese & Rhodes, 2000; Garroutte et al., 2006; Kaufert et al., 1999); and family as mediator and decision-maker (Cassim et al., 2021; Kaufert et al., 1999) found in this review present challenges to the ethical principles of Western biomedicine, namely autonomy and informed consent. The medical system expects HCPs to present themselves and break bad news through a biomedical lens, while “respecting” Indigenous ways. For example, the HCP is expected to obtain informed consent for an action that follows BBN, for example, treatment or palliation, and this action is rooted in the duty to warn and in legal responsibility. This inadvertently prioritizes autonomy over an Indigenous ideal of the center good. This priority was even seen in the studies analyzed. Colclough and Brown (2014) conducted a study exploring end-of-life decision-making; what emerged was that HCPs believed they supported autonomous decision-making, but patients believed the diagnosis was given to them. In the discussion section, the authors elaborated in detail about how informed consent may mean something different for Indigenous patients, and that HCPs need to be aware of that when initiating a discussion.

Informed consent presents further problems to Indigenous ways of knowing. This review highlighted the belief in prophecy (Carrese & Rhodes, 2000; Kaufert et al., 1999) and demonstrated that negative thoughts and words can trigger adverse outcomes, including a negative future diagnosis (Carrese & Rhodes, 2000; Garroutte et al., 2006; Kaufert et al., 1999). Therefore, asking a patient whether they want to know or waive knowing a diagnosis (Rudnick, 2002) may create a culturally unsafe encounter whereby a patient believes a negative outcome may follow. These situations are complex but may be mitigated by following Carrese and Rhodes’ and Kaufert et al.’s suggestion that “no harm is intended” can be stated before beginning a BBN conversation in the context of a trusting relationship.

A complex philosophical discourse could follow from the ideas presented; however, a practical implication is acknowledging that biomedical and Indigenous ways of knowing, when applied to BBN, are complex, and thoughtful action is needed. NPs need to recognize that a spectrum of dual identities exists (Carrese & Rhodes, 2000; Colclough & Brown, 2019; Garroutte et al., 2006); to conduct a robust assessment of the patient’s values (Carrese & Rhodes, 2000; Colclough & Brown, 2014, 2019; Olver et al., 2022); to have self-awareness of their own philosophy, values, and biases (Cassim et al., 2021; Colclough & Brown, 2014; Olver et al., 2022; Rheault et al., 2021); and to use tactful communication practices (Carrese & Rhodes, 2000; Cassim et al., 2021; Colclough & Brown, 2014; Davies, 2014; Garroutte et al., 2006; Hodge et al., 2021; Lillie et al., 2020; Olver et al., 2022; Rheault et al., 2021). This robust approach to care can build a foundation for a trusting relationship with the patient that the patient defines as culturally safe—a reasonable goal for primary care, where many NPs will find themselves working.

Knowing the Risks for Miscommunication and Misunderstanding

There are important considerations for the "hows" of communication. The studies analyzed indicate that good intentions do not ensure good communication. Miscommunication occurs secondary to differing cultural identities and knowledge gaps, emphasizing the need for judicious consideration of both culture and health literacy (Carrese & Rhodes, 2000; Clayton et al., 2007; Colclough & Brown, 2014, 2019; Davies et al., 2014; Olver et al., 2022). If miscommunication is not addressed, it can break the therapeutic relationship and result in suboptimal care.

A common finding in this review was that HCPs often presume that effective communication occurred when it did not. Miscommunication can have devastating outcomes and result in culturally unsafe care. Examples include HCPs confusing positive talk with understanding (Garroutte et al., 2006) and silence with disengagement (Hodge et al., 2021). HCPs also presume that autonomous decision–making occurs when the patients' experience was that the diagnosis was "given" to them (Colclough & Brown, 2014). These issues are especially problematic when considering that miscommunication permeates even study methodologies.

Olver et al. (2022) studied and defined communication success according to the HCP without validation from the local Indigenous population. Beddard-Huber et al. (2021) accepted, without critique, nurses' explanations of culturally safe BBN practices. What if all the conversations HCPs deem successful are culturally unsafe and ridden with misunderstanding, judgment, and patient distress? This is a highly problematic issue, especially considering the already distressing nature of learning that one has a life-altering illness.

Accordingly, it is imperative to consider research methodology and determine how methodology still catalyzes paternalism and inequity (Hayward et al., 2021; Konczi & Bill, 2024). Research that does not have true Indigenous involvement still occurs today. OCAP principles (First Nations Information Governance Centre, n.d.; Konczi & Bill, 2024) may be implemented, and Indigenous ways of knowing may be respected, but these efforts must be analyzed critically and not taken at face value. Furthermore, the presence of Indigenous authorship does not ensure that the methodology is appropriate. NPs need to have a healthy understanding of OCAP principles and watch for application of these principles as they interpret studies involving Indigenous populations.

Health literacy is an essential consideration as it relates to misunderstanding and miscommunication. Health literacy was mentioned in multiple studies in this review (Beddard-Huber et al., 2021; Carrese & Rhodes, 2000; Cassim et al., 2021; Colclough & Brown, 2014; Garroutte et al., 2006; Olver et al., 2022). Most research on the health literacy of Indigenous adults focuses on addressing a deficit rather than considering its interplay with culture and Indigenous ways of knowing (Boot & Lowell, 2019; Nash & Arora, 2021). It is important not to attribute a patient's misunderstanding to poor health literacy but to consider that shared news may carry a different meaning beyond the HCP's ways of knowing. Davies et al. (2014) captured this when they presented silent HBV as a metaphor that connotes sorcery for the Yolŋu people.

Miscommunication issues and the focus on improving patient's health literacy as a solution highlight the power differentials (Boot & Lowell, 2019) and paternalism in health care and the unique Indigenous experience with it that is secondary to colonization. From this perspective, what the NP thinks may be shared knowledge is at risk of becoming coercion. The NP must enter all patient interactions knowing they may misinterpret the patient's words, non-verbal cues, and intent.

The role of the NP is to provide culturally safe care, even though navigating miscommunication is hazardous. Thankfully, there are some strategies the NP can use. Assessing for accurate comprehension, lack of distress, and satisfaction with care are essential to BBN conversations but the way in which these are done can influence whether a conversation is culturally safe. Using appropriate communication tools and maintaining awareness of best practices which acknowledge cultural diversity are especially pertinent methods when considering these emotionally charged conversations cross-culturally and knowing the risk of miscommunication (Beddard-Huber, 2021; Clayton et al., 2007; Fahner et al., 2019; Lillie et al., 2020; Olver et al., 2022).

Complexities of Hope and Fatalism

NPs should understand that *hope* may mean something different to what they personally comprehend in their ways of knowing. Hope and positivity carry greater meaning than optimism in many Indigenous cultures, and they can be prophetic (Carrese & Rhodes, 2000; Cassim et al., 2021; Kaufert et al., 1999). Therefore, BBN conversation can be taboo if not navigated in a culturally safe manner. There is strong power in communicating negative health information; if done incorrectly, it can contribute to IHT, an increased sense of fatalism, and poorer health outcomes. There is strong power in communicating negative health information; if done incorrectly, it can contribute to IHT, an increased sense of fatalism, and poorer health outcomes. Inversely, there is great power in communicating positive information (Garroutte et al., 2006), hope (Cassim et al., 2021; Kaufert et al.,1999), maintaining a center good (Mackay, 2022), and hózho – thinking and speaking in the Beauty Way (Carrese & Rhodes, 2000).

Limitations

Multiple limitations exist in the integrative review design and methodology. First, only two databases were used in the official search strategy. Preliminary searches were done on PubMed, Native Health Database, PsychInfo, and Epistemonikos, with no results yielded; systematic search strategies were not done due to time constraints. Although it would have been ideal, X̱wi7x̱wa Library—an Indigenous library at the University of British Columbia—was not consulted. Another limitation was the possibility of skewed results due to changing the research question from serious illness conversations to BBN after writing began, and then going back to rerun those searches.

The literature in this integrative review is available on mainstream academic databases. Wisdom obtained from non-indexed literature and other sources of Indigenous knowledge was not sourced. All findings are tenuous and must be interpreted cautiously because of the diversity of Indigenous populations represented in this integrative review. Findings from neighbouring nations cannot be generalized; therefore, generalizing findings from many nations across four countries is unreasonable. Furthermore, only 12 studies were included, limiting this review’s generalizability.

Conclusion

Indigenous adults' experience with BBN varies, but it arrives against the backdrop of a biomedical and colonial system that delegitimizes Indigenous ways of knowing. Supporting culturally appropriate BBN, therefore, may not come naturally to the NP trained in and held accountable to biomedical theories and policies. Despite an increasing emphasis on culturally safe practice (CBC News, 2023; Curtis et al., 2019), finding ways to put this into action is often challenging. This integrative review aimed to give NPs ideas to consider before engaging in BBN conversations, but it is not a prescription for action. The review findings demonstrate that understanding how a patient may make meaning of the BBN conversation is paramount to providing culturally safe care. However, recommendations of how to do this are offered with acknowledgement that it is culturally unsafe to describe commonalities of another group of cultures, because it results in "othering" (Curtis et al., 2019). Future research is needed to explore the topic of BBN as it pertains to specific Indigenous tribes and nations.

References

Advisory Committee on Human Radiation Experiments. (1994). *Chapter 12: The Iodine 131 experiment in Alaska*. https://bioethicsarchive.georgetown.edu/achre/final/chap12_4.html

Ahenakew, C. (2011). The birth of the “Windigo”: The construction of Aboriginal health in biomedical and traditional Indigenous models of medicine. *Critical Literacy: Theories & Practices, 5*(1), 14–26. https://www.academia.edu/832455/The_birth_of_the_Windigo_The_construction_of_Aboriginal_health_in_biomedical_and_traditional_Indigenous_models_of_medicine

Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—A six-step protocol for delivering bad news: Application to the patient with cancer. *The Oncologist*, *5*(4), 302–311. https://academic.oup.com/oncolo/article/5/4/302/6386019?login=false

Bartlett, C., Marshall, M., & Marshall, A. (2012). Two-Eyed Seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences, 2*, 331-340. https://www.doi.org/10.1007/s13412-012-0086-8

Beddard-Huber, E., Gaspard, G., & Yue, K. (2021). Adaptations to the serious illness conversation guide to be more culturally safe. *International Journal of Indigenous Health, 16*(1), 38. https.//www.doi.org/10.32799/ijih.v16i1.33192

Berkey, F. J., Wiedemer, J. P., & Vithalani, N. D. (2018). Delivering bad or life-altering news. *American Family Physician, 98*(2), 99–104.

Boot, G. R., & Lowell, A. (2019). Acknowledging and promoting Indigenous knowledges, paradigms, and practices within health literacy-related policy and practice documents across Australia, Canada, and New Zealand. *International Indigenous Policy Journal, 10*(3), 1–28.

Campbell S., Dorgan M., & Tjosvold, L. (2014). Creating provincial and territorial search filters to retrieve studies related to Canadian Indigenous peoples from Ovid MEDLINE. *Journal of the Canadian Health Libraries Association, 35*(1), 5–10. https://www.doi.org/10.5596/c14-10

Canadian Medical Association (CMA). (2024). *CMA apology to Indigenous Peoples: Historical and ethical review report.* https://digitallibrary.cma.ca/link/digitallibrary585

Carlson, K. T., & Stó:lō Heritage Trust. (1997). *You are asked to witness: The Stó:lō in Canada's Pacific Coast history*. Stó:lō Heritage Trust.

Carrese, J. A., & Rhodes, L. A. (2000). Bridging cultural differences in medical practice. The case of discussing negative information with Navajo patients. *Journal of General Internal Medicine, 15*(2), 92–6. https://www.doi.org/10.1046/j.1525-1497.2000.03399.x

Cassim, S., Kidd, J., Keenan, R., Middleton, K., Rolleston, A., Hokowhitu, B., Firth, M., Aitken, D., Wong, J., & Lawrenson, R. (2021). Indigenous perspectives on breaking bad news: Ethical considerations for healthcare providers. *Journal of Medical Ethics, 47*(12), e62 https://doi.org/10.1136/medethics-2020-106916

CBC News. (2023, September 13). Bill prompts call for Quebec to recognize systemic racism in health system. https://www.cbc.ca/news/canada/montreal/bill-quebec-recognize-systemic-racism-in-health-system-1.6965025#:~:text=He%20said%20systemic%20racism%20is,the%20word%2C%22%20said%20Gaudreault

Clayton, J. M., Hancock, K. M., Butow, P. N., Tattersall, M. H. N., & Currow, D. C. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Medical Journal of Australia, 187*(8), 76–108. https://www.doi.org/10.5694/j.1326-5377.2007.tb01100.x

Colclough, Y. Y., & Brown, G. M. (2014). End-of-life treatment decision making: American Indians' perspective. *The American Journal of Hospice & Palliative Care, 31*(5), 503–512. https://doi.org/10.1177/1049909113489592

Colclough, Y. Y., & Brown, G. M. (2019). Moving toward openness: Blackfeet Indians' perception changes regarding talking about end of life. *The American Journal of Hospice & Palliative Care, 36*(4), 282–289. https://doi.org/10.1177/1049909118818255

Covidence [Computer software]. (2025). https://www.covidence.org/

Critical Appraisal Skills Programme (2024). *CASP checklist: For qualitative research*. [online] https://casp-uk.net/casp-checklists/CASP-checklist-qualitative-2024.pdf

Curtis, E., Jones, R., Tipene-Leach, D., Walker, C., Loring, B., Paine, S.-J., & Reid, P. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health, 18*(174), 1–17. https://doi.org/10.1186/s12939-019-1082-3

Davies, J., Bukulatjpi, S., Sharma, S., Davis, J., & Johnston, V. (2014). "Only your blood can tell the story"—A qualitative research study using semi-structured interviews to explore the hepatitis B related knowledge, perceptions and experiences of remote dwelling Indigenous Australians and their health care providers in northern Australia. *BMC Public Health, 14*(1), 1–23. https://doi.org /10.1186/1471-2458-14-1233

Dawson, C. R., Hanna, L., & Jawetz, E. (1967). Controlled treatment trials of trachoma in American Indian children. *Lancet, 290*(7523), 961–964. https://doi.org/10.1016/S0140-6736(67)90796-9

Dunaievska, O. V., & Chaiuk, T. A. (2020). Modifying "breaking bad news" communication: Cross-cultural and cognitive-semantic approaches. *Academic Journal of Interdisciplinary Studies, 9*(2), 1–14. https://doi.org/10.36941/ajis-2020-0017

Fahner, J. C., Beunders, A. J. M., van der Heide, A., Rietjens, J. A. C., Vanderschuren, M. M., van Delden, J. J. M., & Kars, M. C. (2019). Interventions guiding advance care planning conversations: A systematic review. *Journal of the American Medical Directors Association, 20*(3), 227–248. https://doi.org/10.1016/j.jamda.2018.09.0

Finzsch, N. (2008). "[. . .] Extirpate or remove that vermine": genocide, biological warfare, and settler imperialism in the eighteenth and early nineteenth century. *Journal of Genocide Research, 10*(2), 215–232. https://doi.org/10.1080/14623520802065446

First Nations Information Governance Centre. (n.d.). *The First Nations principles of OCAP®.* https://fnigc.ca/ocap-training/

Fisher, J., Russell, J., Browne, A., & Burkholder, L. (2018). *Biomedical ethics: A Canadian focus* (3rd ed.). Oxford University Press.

Garroutte, E.M., Kunovich, R.M., Buchwald, D., & Goldberg, J. (2006). Medical communication in older American Indians: Variations by ethnic identity. *Journal of Applied Gerontology*, *25*(1), 27S–43S. https://doi.org/10.1177/0733464805282725

Gone, J. P., Hartmann, W. E., Pomerville, A., Wendt, D. C., Klem, S. H., & Burrage, R. L.

(2019). The impact of historical trauma on health outcomes for indigenous populations in the USA and Canada: A systematic review. *American Psychologist, 74*(1), 20–35. https://doi/org/10.1037/amp0000338

Griffiths, K., Coleman, C., Lee, V., & Madden, R. (2016). How colonisation determines social justice and Indigenous health—A review of the literature. *Journal of Population Research, 33*(1), 9–30. https://doi.org/10.1007/s12546-016-9164-1

Harman, S.M., & Arnold, R. M. (2024). Discussing serious news. *UpToDate*. Retrieved April 20, 2025, from https://www.uptodate.com/contents/discussing-serious-news?search=Discussing%20serious%20news&source=search_result&selectedTitle=1%7E23&usage_type=default&display_rank=1

Hayward, A., Sjoblom, E., Sinclair, S., & Cidro, J. A new era of Indigenous research: Community-based Indigenous research ethics protocols in Canada. *Journal of Empirical Research on Human Research Ethics, 16*(4), 403–417. https://doi:10.1177/15562646211023705

Hodge, F. S., Itty, T. L., Samuel-Nakamura, C., & Cadogan, M. (2020). We don't talk about it: Cancer pain and American Indian survivors. *Cancers, 12*(7), 1932. https://doi.org/10.3390/cancers12071932

Holmes, S. N., & Illing, J. (2021). Breaking bad news: Tackling cultural dilemmas. *BMJ Supportive & Palliative Care, 11*(2), 128–132. https://doi.org/10.1136/bmjspcare-2020

Jalali, R., Jalali, A., & Jalilian, M. (2023). Breaking bad news in medical services: A comprehensive systematic review. *Heliyon, 9*(4), e14734. https://doi.org/10.1016/j.heliyon.2023.e14734 002700

Jeffery, T., Kurtz, D. L.M., & Jones, C.A. (2021). Two-Eyed Seeing: Current approaches, and discussion of medical applications. *British Columbia Medical Journal 63*(8), 321–325. https://bcmj.org/articles/two-eyed-seeing-current-approaches-and-discussion-medical-applications

Joo-Castro L, & Emerson A. (2021) Understanding historical trauma for the holistic care of Indigenous populations: A scoping review. *Journal of Holistic Nursing, 39*(3), 285–305. https://doi:10.1177/0898010120979135

Kaufert J. M., Putsch R. W., & Lavallee M. (1999). End-of-life decision making among Aboriginal Canadians: Interpretation, mediation, and discord in the communication of "bad news." *Journal of Palliative Care, 15*(1), 31–38. https://doi.org/10.1177/082585979901500105

Kidd, J., Cassim, S., Rolleston, A., Keenan, R., Lawrenson, R., Sheridan, N., Warbrick, I., Ngaheu, J., & Hokowhitu, B. (2021). Hā Ora: Reflecting on a Kaupapa Māori community-engaged co-design approach to lung cancer research. *International Journal of Indigenous Health, 16*(2), 192. https://doi.org/10.32799/ijih.v16i2.33106

Konczi, A.E., & Bill, L. (2024). Advancing First Nations principles of OCAP®. In G. Garvey (Ed.) *Indigenous and tribal peoples and cancer* (pp. 37–39). Springer. https://doi.org/10.1007/978-3-031-56806-0_8

Kotalik, J., & Martin, G. (2016). Aboriginal health care and bioethics: A reflection on the teaching of the seven grandfathers. *The American Journal of Bioethics, 16*(5), 38–43. https://doi.org/10.1080/15265161.2016.1159749

Lakin, J. R., Koritsanszky, L. A., Cunningham, R., Maloney, F. L., Neal, B. J., Paladino, J., Palmor, M. C., Vogeli, C., Ferris, T. G., Block, S. D., Gawande, A. A., & Bernacki, R. E. (2017). A systematic intervention to improve serious illness communication in primary care. *Health Affairs, 36*(7), 1258–1264. https://doi.org/10.1377/hlthaff.2017.0219

Lange, R. (2018). Te hauora Māori i mua—history of Māori health. In *Te Ara—the Encyclopedia of New Zealand*. http://www.TeAra.govt.nz/en/te-hauora-maori-i-mua-history-of-maori-health

Lillie, K. M., Dirks, L. G., Curtis, J. R., Candrian, C., Kutner, J. S., & Shaw, J. L. (2020). Culturally adapting an advance care planning communication intervention with American Indian and Alaska Native people in primary care. *Journal of Transcultural Nursing, 31*(2), 178–187. https://doi.org/10.1177/1043659619859055

Mackay, R. (2022). Tlacoqualli in Monequi “the Center Good”: A brief consideration of indigenous bioethics. *Voices in Bioethics, 8*. https://doi.org/10.52214/vib.v8i.10151

Mahendiran, M., Yeung, H., Rossi, S., Khosravani, H., & Perri, G. A. (2023). Evaluating the effectiveness of the SPIKES Model to break bad news—A systematic review. *The American Journal of Hospice & Palliative Care, 40*(11), 1231–1260. https://doi.org/10.1177/10499091221146296

Nash, S., & Arora, A. (2021). Interventions to improve health literacy among Aboriginal and Torres Strait Islander Peoples: A systematic review. *BMC Public Health 21*, 248. https://doi.org/10.1186/s12889-021-10278-x

National Museum Australia. (2022). *Defining moments: Smallpox epidemic*. https://www.nma.gov.au/defining-moments/resources/smallpox-epidemic

Olver, I., Gunn, K. M., Chong, A., Knott, V., Spronk, K., Cominos, N., & Cunningham, J.

(2022). Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: A qualitative study. *Supportive Care in Cancer, 30*(1), 431–438. https://doi.org/10.1007/s00520-021-06430-3

Pacheco, C. M., Daley, S. M., Brown, T., Filippi, M., Greiner, A., & Daley, C. M. (2013). Moving forward: Breaking the cycle of mistrust between American Indians and researchers. *American Journal of Public Health, 103*(12), 2152–2159. https://doi/org/10.2105/AJPH.2012.301480

Park, J. (2021, October 20). *Health reports: Morality among First Nations people*, *2006 to 2016.* Statistics Canada. https://www.doi.org/10.25318/82-003-x202101000001-eng

Radbruch, L., De Lima, L., Knaul, F., Wenk, R., Ali, Z., Bhatnaghar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E. C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., Foley, K., & Goh, C., . . . Pastrana, T. (2020). Redefining palliative care—A new consensus-based definition. *Journal of Pain and Symptom Management, 60*(4), 754–764. https://doi.org/10.1016/j.jpainsymman.2020.04.027

Rethlefsen, M. L., Kirtley, S., Waffenschmidt, S., Ayala, A. P., Moher, D., Page, M. J., & Koffel, J. B. (2021). PRISMA-S: An extension to the PRISMA statement for reporting literature searches in systematic reviews. *Systematic Reviews, 10*(1), 174–200. https://www.doi.org/10.5195/jmla.2021.962

Rheault, H., Coyer, F., & Bonner, A. (2021). Time to listen: Chronic disease yarning with Aboriginal and Torres Strait Islander peoples living in remote Australia. *Collegian, 28*(1), 10–17. https://doi.org/10.1016/j.colegn.2020.06.001

Robson, C. (2018). Medical experimentation and indigenous intergenerational memory in the context of twentieth-century Hansen's disease treatment in Australia. *Health & History: Journal of the Australian & New Zealand Society for the History of Medicine, 20*(2), 54–74. https://doi.org/10.5401/healthhist.20.2.0054

Rogers-LaVanne, M.P., Bader, A.C., de Flamingh, A. et al. (2022). Association between gene methylation and experiences of historical trauma in Alaska Native peoples. *International Journal for Equity in Health 22*, 182. https://doi.org/10.1186/s12939-023-01967-7

Rudnick A. (2002). Informed consent to breaking bad news. *Nursing Ethics, 9*(1), 61–66. https://doi.org/10.1191/0969733002ne481oa

Smallwood, R., Woods, C., Power, T., & Usher, K. (2020) Understanding the impact of historical trauma due to colonization on the health and well-being of Indigenous young peoples: A systematic scoping review. *Journal of Transcultural Nursing, 32*(1):59-68. https://doi.org/10.1177/1043659620935955

Thom, R. R. M., & Grimes, A. (2022). Land loss and the intergenerational transmission of wellbeing: The experience of iwi in Aotearoa New Zealand. *Social Science & Medicine*, *296*, 1–9. https://doi.org/10.1016/j.socscimed.2022.114804

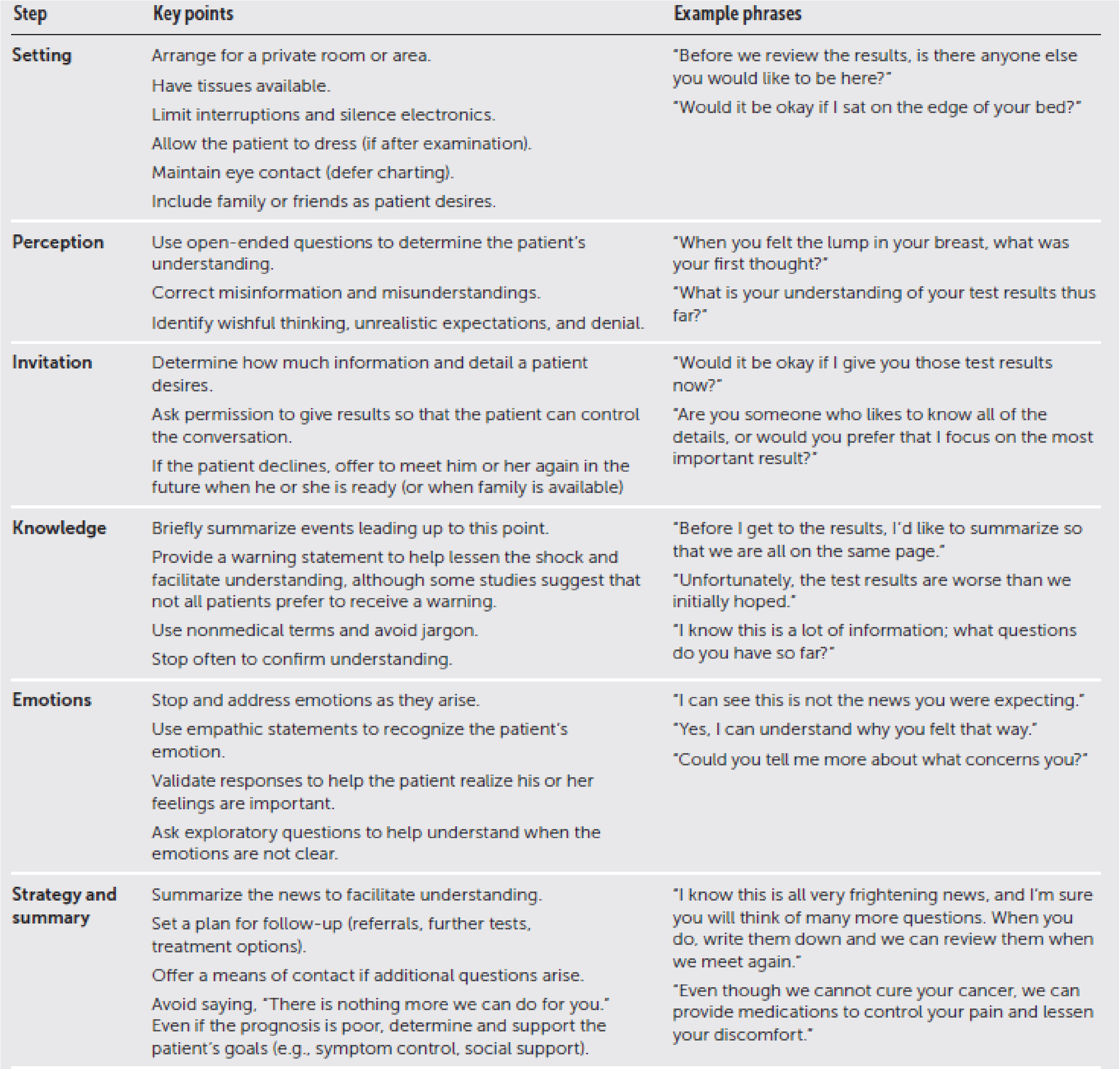
Truth and Reconciliation Commission of Canada. (2015). *Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada*. McGill-Queen's University Press. https://nccdh.ca/resources/entry/honouring-the-truth-reconciling-for-the-future

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing, 52*(5), 546–553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

Zotero [Computer software]. (2025). https://www.zotero.org/

Table 1

SPIKES Protocol for Delivering Bad News



Step	Key points	Example phrases
Setting	Arrange for a private room or area. Have tissues available. Limit interruptions and silence electronics. Allow the patient to dress (if after examination). Maintain eye contact (defer charting). Include family or friends as patient desires.	"Before we review the results, is there anyone else you would like to be here?" "Would it be okay if I sat on the edge of your bed?"
Perception	Use open-ended questions to determine the patient's understanding. Correct misinformation and misunderstandings. Identify wishful thinking, unrealistic expectations, and denial.	"When you felt the lump in your breast, what was your first thought?" "What is your understanding of your test results thus far?"
Invitation	Determine how much information and detail a patient desires. Ask permission to give results so that the patient can control the conversation. If the patient declines, offer to meet him or her again in the future when he or she is ready (or when family is available)	"Would it be okay if I give you those test results now?" "Are you someone who likes to know all of the details, or would you prefer that I focus on the most important result?"
Knowledge	Briefly summarize events leading up to this point. Provide a warning statement to help lessen the shock and facilitate understanding, although some studies suggest that not all patients prefer to receive a warning. Use nonmedical terms and avoid jargon. Stop often to confirm understanding.	"Before I get to the results, I'd like to summarize so that we are all on the same page." "Unfortunately, the test results are worse than we initially hoped." "I know this is a lot of information; what questions do you have so far?"
Emotions	Stop and address emotions as they arise. Use empathic statements to recognize the patient's emotion. Validate responses to help the patient realize his or her feelings are important. Ask exploratory questions to help understand when the emotions are not clear.	"I can see this is not the news you were expecting." "Yes, I can understand why you felt that way." "Could you tell me more about what concerns you?"
Strategy and summary	Summarize the news to facilitate understanding. Set a plan for follow-up (referrals, further tests, treatment options). Offer a means of contact if additional questions arise. Avoid saying, "There is nothing more we can do for you." Even if the prognosis is poor, determine and support the patient's goals (e.g., symptom control, social support).	"I know this is all very frightening news, and I'm sure you will think of many more questions. When you do, write them down and we can review them when we meet again." "Even though we cannot cure your cancer, we can provide medications to control your pain and lessen your discomfort."

Note. The table is from Berkey, F. J., Wiedemer, J. P., & Vithalani, N. D. (2018). Delivering bad or life-altering news. *American Family Physician, 98*(2), 99–104.

Table 2

PRISMA-S Checklist

SECTION/TOPIC	ITEM #	Checklist item
INFORMATION SOURCES AND METHODS		
Database name	1	Name each individual database searched, stating the platform for each.
Multi-database searching	2	If databases were searched simultaneously on a single platform, state the name of the platform, listing all the databases searched.
Study registries	3	List any study registries searched.
Online resources and browsing	4	Describe any online or print source purposefully searched or browsed (e.g., tables of contents, print conference proceedings, websites), and explain how this was done.
Citation searching	5	Indicate whether cited references or citing references were examined, and describe any methods used for locating cited or citing references (e.g., browsing reference lists, using a citation index, setting up email alerts for references citing included studies).
Contacts	6	Indicate whether additional studies or data were sought by contacting authors, experts, manufacturers, or others.
Other methods	7	Describe any additional information sources or search methods used.
SEARCH STRATEGIES		
Full search strategies	8	Include the search strategies for each database and information source, copied and pasted exactly as run.
Limits and restrictions	9	Specify that no limits were used, or describe any limits or restrictions applied to a search (e.g., date or time period, language, study design) and provide justification for their use.
Search filters	10	Indicate whether published search filters were used (as originally designed or modified), and if so, cite the filter(s) used.

Prior work	11	Indicate when search strategies from other literature reviews were adapted or reused for a substantive part or all the search, citing the previous review(s).
Updates	12	Report the methods used to update the search(es), (e.g., rerunning searches, email alerts).
Dates of searches	13	For each search strategy, provide the date when the last search occurred.
PEER REVIEW		
Peer Review	14	Describe any search peer review process.
MANAGING RECORDS		
Total Records	15	Document the total number of records identified from each database and other information sources.
Deduplication	16	Describe the processes and any software used to deduplicate records from multiple database searches and other information sources.

Note. The table was copied verbatim from Rethlefsen, M. L., Kirtley, S., Waffenschmidt, S., Ayala, A. P., Moher, D., Page, M. J., & Koffel, J. B. (2021). PRISMA-S: An extension to the PRISMA Statement for reporting literature searches in systematic reviews. *Systematic Reviews, 10*(1), 174–200. https://www.doi.org/10.5195/jmla.2021.962

Table 3

Search Term Strategy

	Communication	AND	Poor Health Condition	AND	Indigenous peoples	NOT
MeSH terms	Truth Disclosure OR Advance Care Planning OR Decision Making, Patient		Advance Care Planning OR Palliative Care OR Attitude to Death OR Terminal Care		Indigenous Peoples OR Indigenous Health	Suicidal Ideation
Keywords	*I intentionally did no keywords. Communication is a multidisciplinary concept that could be mentioned even once in many irrelevant articles. I wanted some* ***emphasis*** *on communication, thus I performed it as an abstract title search.*		Advance* Care Plan* OR Serious Illness Conversation* OR End of Life OR Bad News OR Breaking Bad News		**Campbell Dorgan, and Tjosvold's filters–each varied in length, from 24 to 1582 words** OR First Nation* OR Inuit OR Metis OR Indian OR Native, Native American OR Torre Strait Islander* OR Aboriginal Australian OR Maori	India OR Plant
Abstract/ Title	Communicat* OR Communcat* skill* OR Conversation OR Truth Disclosure OR Discussion Talk*		palliative approach OR prognosis goal*of care OR SPIKES framework OR breaking bad news			
	("goals of care") OR ("serious illness conversation*") OR ("serious illness communication") OR ("critical illness conversation*") OR ("bad news") OR ("breaking bad news")					

Table 4

Study Analysis: Part 1 of 2

Author, (Year), Title	Tribe or Nation	Participant Demographics	Community Approval	Member Checking	Community Feedback Sought	Informed re: Health care*	Recruitment Concerns	Possible Bias
Beddard-Huber et al. (2021) Adaptations to the Serious Illness Conversation Guide to Be More Culturally Safe	Two undisclosed tribes, British Columbia (Canada).	Indigenous people from two First Nations communities in British Columbia, Canada: (*n* = 20, *n* = 15) HCPs, ethnicity not identified (a) Workshop: (*n* = 61); follow-up survey (*n* = 14) (b) Two nurse sharing circles: (*n* = 4, *n* = 6)	NO	NO: validated 1st communities findings via the 2nd	NO	N/A—no patients	YES. HCPs may have felt obliged to participate.	Nurse's perspective of cultural safety is the anthesis of cultural safety.
Carrese & Rhodes (2000) Bridging cultural differences in medical practice: The case of discussing negative information with Navajo patients	Navajo (USA)	Indigenous: ▫patients (*n* = 20) ▫traditional healers (*n* = 6) HCPs—undisclosed ID (*n* = unknown)	NO	NO	YES	NO	Possibly. Not elaborated on; the lead author is a physician.	Not obvious.
Cassim et al. (2021) Indigenous perspectives on breaking bad news: ethical considerations for health care providers	Four Māori districts: Waikato, Bay of Plenty, Lakes and Tairāwhiti (NZ)	Indigenous interviews: ▫patients (*n* = 16) ▫ family (whānau) members (*n* = 32) Indigenous community focus groups/meeting (hui): ▫ meetings (*n* = 9; 2–3 with each community) ▫ participants per meetings (*n* = 8–21)	YES, even built relationships with the communities. Did "organize" hui with community stakeholders	NO	YES	NO	Initial recruitment by HCPS providing care to said patients: respiratory or cancer nurse specialists	Yes. Perhaps related to recruitment strategy. Research led by the institution where the study was conducted.
Colclough and Brown (2014) End-of-life treatment decision-making: American Indians' perspective.	Blackfoot (USA)	Indigenous: ▫patients (*n* = 20) ▫ family member (*n* = 32) ▫HCPs (*n* = 5) Non-Indigenous: ▫HCPs (*n* = 1)	YES	NO	YES—presentations to the tribal council and community	YES—indirectly confirmed this.	NO	HCPs are employees.
Colclough and Brown (2019) Moving toward openness: Blackfeet Indians' perception changes regarding talking about end of life	Blackfoot (USA)	Indigenous: ▫ Recognized Elder, for interview (*n* =10) ▫adult survey participants (*n* = 102)	YES, asked by the community to do it	NO	YES	NO	NO	Rushed data analysis re: trying to justify hospice, based on data.
Davies et al. (2014) "Only your blood can tell the story"—A qualitative research study using semi-	Yolŋu people (AUS)	Indigenous: ▫clients with HBV (*n* = 11) ▫community members (*n* = 9) ▫HCPs (*n* = 4)	MINIMAL, got approval from an Indigenous	YES, one author returned to (some)	YES (consultation, reflection and discussion	YES	Most clients were recruited from patients and the	Possibly felt an obligation to participate. Yet, did conduct interviews

structured interviews to explore hepatitis B related knowledge		Non-Indigenous: ▫HCPs (*n* = 8)	health organization	participants to clarify findings	with the community throughout each iterative cycle.)		hospital liver unit.	away from clinical care (time and space)
Garroutte et al. (2006) Medical communication in older American Indians: Variations by ethnic identity	Cherokee (USA)	One unit at a clinic dedicated to chronic illness management Indigenous: ▫patients (*n* = 102) ▫HCP: primary care (*n* = 4) Non-Indigenous :▫HCP: primary care (*n* = 3)	YES	NO	NO	NO	Done in the waiting room. HCPS maybe felt obliged. Did not explain this in detail.	Obligation to participate
Hodge et al. (2021) We don’t bring our burdens home: American Indian response to cancer diagnosis	Five reservations in Southwest USA, tribes undisclosed	Indigenous: ▫ 132 clients (cancer survivors)	NO	NO	NO	YES - overtly stated this to participants	No. Recruitment involved patients calling a number if interested, re: flyers.	Poor methods section and goal of creating an intervention with this data, could bias interpretation of results.
Kaufert et al. (1999) End-of-life decision-making among aboriginal Canadians: Interpretation, mediation, and discord in the communication of “bad news”	Cree and Ojibway (CANADA)	▫ Patients (*n* = 2) ▫ Family/caregivers (*n*= unknown), ▫ Interpreters (*n* = 2) ▫ HCPs (*n* = unknown)	NO	NO	NO	NO	YES, re: means of recruitment not presented.	No quotes, meaning could be misconstrued to the story the author wants to tell
Lillie et al. (2020) Culturally adapting an advance care planning communication intervention with American Indian and Alaska Native people in primary care	*Health care hub* for Alaskan Native and in American Indians in Albuquerque (USA)	Indigenous: ▫ patient/caregiver (*n* = 19) ▫ HCP/ administrator (*n* = 4) Non-Indigenous ▫ HCP/administrator (*n* = 12)	MINIMAL- from tribal health leaders.	YES, the "follow-up" cognitive interview was member-checking.	SOMEWHAT. Had community advisory board.	NO	YES for HCPs. Could have felt obliged as employees	Research department of these health-care organizations ran the study. Bias, re: purpose was to adapt a tool
Olver et al. (2022) Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: a qualitative study	N/A: HCPs in Northern Territory and South AUS	Indigenous: ▫ HCPs (*n* = 5) Non-Indigenous: ▫HCPs (*n* = 18)	NO, not as applicable re: HCP-focused study	N/A	N/A	N/A: no patients	YES.	All HCPs interviewed were oncology staff, a few being Aboriginal health workers.
Rheault et al. (2020) Time to listen: Chronic disease yarning with Aboriginal and Torres Strait Islander peoples living in remote Australia	Kalkadoon people (AUS)	Indigenous: ▫patients (*n* = 20)	YES	NO: rationalized it was not a part of yarning methodology	YES: preliminary research only	YES: important re: clients recruited via the chronic disease clinic	At a chronic disease clinic. Approached by Aboriginal Health Worker. Hopefully, no coercion.	No obvious bias

Note: * *Participants* were informed that health care is not contingent upon study participation.

Table 5

Study Analysis: Part 2 of 2

Author, (Year), Title	Appropriate Research Method	Focus: End of Life, ACP, or Other	Indigenous Authorship	OCAP Effort (1–3)*	Data Analysis Rigour	Data Saturation Reached (as per Author)	Overall Quality of Study (1–5)**
Beddard-Huber et al. (2021) Adaptations to the Serious Illness Conversation Guide to Be More Culturally Safe	NO: quality improvement strategy. Appropriate for its purposes, not for a robust inclusion in this literature review	Other: SIC guide	NO	WEAK (1/3)	Decent: two-author process of independent review, discuss, then refine. No exact methodology	NO	2
Carrese & Rhodes (2000) Bridging cultural differences in medical practice: The case of discussing negative information with Navajo patients	YES: focused ethnography	Other: negative health info “generally”	NO	OKAY (2/3)	Good: multiple steps to ensure trustworthiness, even hired an anthropologist.	NO	4
Cassim et al. (2021) Indigenous perspectives on breaking bad news: ethical considerations for health-care providers	YES: Kaupapa Māori (co-design) approach	Other: explore the experiences of lung cancer patients/families receiving bad news	YES, alluded to it	STRONG (3/3)	Questionable: minimal elaboration on how they did.	NO	4
Colclough & Brown (2014) End-of-life treatment decision-making: American Indians’ perspective.	YES: community-based participatory research (CBPR), grounded theory	EOL	YES, from the tribe itself	OKAY (2/3)	Strong: even pilot-tested their questions	YES: stopped recruiting once they reached it	4
Colclough & Brown (2019) Moving toward openness: Blackfeet Indians’ perception changes regarding talking about end of life	YES: CBPR, mixed methods implied	EOL	YES	OKAY (2/3)	Only the principal investigator analyzed data, granted using three methods.	NO	3
Davies et al. (2014) “Only your blood can tell the story”: A qualitative research study using semi-structured interviews to explore hepatitis B related knowledge.	YES: participatory action research project	Other: perception and communication with HCPs re: chronic disease (hepatitis B)	YES	OKAY (2/3)	Good: Two authors. Data immersion. Coding-based categories/a coding model. Clarification.	NO	4

Garroutte et al. (2006) Medical communication in older American Indians: Variations by ethnic identity	YES: mixed methods (possibly convergent concurrent with a quantitative focused analysis).	Other: ethnic ID and communication patterns	NO	WEAK (1/3)	Good use of descriptive statistics, professional coding	NO	3
Hodge et al. (2021) We don't bring our burdens home: American Indian response to cancer diagnosis	YES: qualitative	Other: cancer pain management and associated cultural constructs	NO	WEAK (1/3)	Poor elaboration on method, unsure of how rigorous the data analysis was	NO	3
Kaufert et al. (1999) End-of-life decision-making among aboriginal Canadians: Interpretation, mediation, and discord in the communication of "bad news"	YES: ethnography	EOL	NO	WEAK (1/3)	Poor	NO	2
Lillie et al. (2020) Culturally adapting an advance care planning communication intervention with American Indian and Alaska Native people in primary care	YES	ACP	YES: led by Indigenous organization research department	STRONG (3/3)	Good: Two researchers independently did coding, etc. Regularly involved the advisory board.	NO	3
Olver et al. (2022) Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: A qualitative study	YES: semistructured interviews	Other: communication about cancer	YES	WEAK (1/3)	Strong rigour and overall methodology, had three coders reach consensus.	YES	3
Rheault et al. (2020) Time to listen: Chronic disease yarning with Aboriginal and Torres Strait Islander peoples living in remote Australia	YES: yarning interview = Indigenous methodology	Other: chronic disease experience (with communication being a big theme)	NO	STRONG (3/3)	Well done. Use of two investigators, covered ideas of trustworthiness, credibility, confirmability.	YES	5

Note. Writer's interpretation. *OCAP: 1 (WEAK) = no to minimal effort to obtain Indigenous involvement feedback; 2 (OKAY) = some effort; 3 (STRONG) = comprehensive and regular effort.
** Overall quality of study based on writers' interpretation of research methods, findings, and analysis: 1= poor quality, 2 = okay quality, 3 = acceptable quality, 4 = good quality, 5 = excellent quality

Table 6

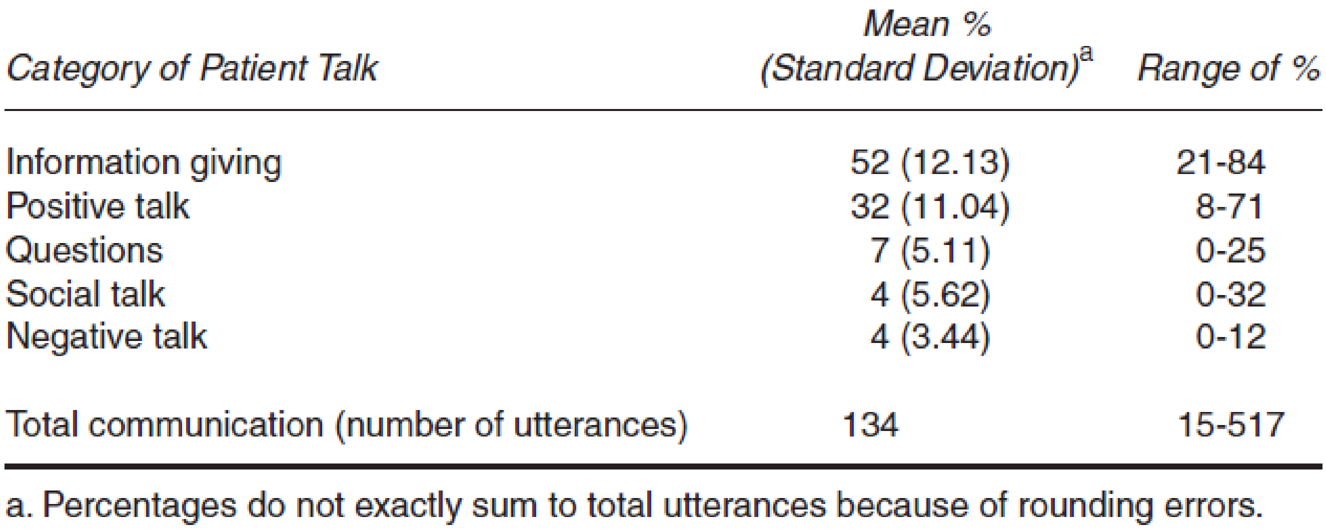
Key Ideas Present in Studies

Author, (Year), Title	Ideas present:*	
Beddard-Huber et al. (2021) Adaptations to the Serious Illness Conversation Guide to Be More Culturally Safe	(a) YES, minimal (b) YES, minimal (c) YES	(d) NO (e) NO (f) YES
Carrese & Rhodes (2000) Bridging cultural differences in medical practice: The case of discussing negative information with Navajo patients	(a) YES (b) NO (c) NO	(d) YES, indirectly (e) YES ++ (f) NO
Cassim et al. (2021) Indigenous perspectives on breaking bad news: Ethical considerations for healthcare providers	(a) YES (b) NO (c) NO, vague reference r/t respect	(d) NO (e) NO (f) NO, vague reference to plain language
Colclough & Brown (2014) End-of-life treatment decision-making: American Indians' perspective	(a) YES, minimal (b) YES, minimal (c) YES+	(d) YES++ (e) NO (f) YES, indirectly
Colclough & Brown (2019) Moving toward openness: Blackfeet Indians' perception changes regarding talking about end of life	(a) NO (b) NO (c) NO	(d) NO (e) YES (f) NO
Davies et al. (2014) "Only your blood can tell the story"—A qualitative research study using semi-structured interviews to explore the hepatitis B related knowledge, perceptions and experiences of remote dwelling Indigenous Australians…	(a) NO (b) YES (c) NO	(d) YES++ (e) YES ++ (f) YES++
Garroutte et al. (2006) Medical communication in older American Indians: Variations by ethnic identity	(a) YES, minimal (b) NO (c) NO	(d) YES (e) YES, minimal (f) NO
Hodge et al. (2021) We don't bring our burdens home: American Indian Response to cancer diagnosis	(a) NO (b) YES++ (c) YES, indirectly	(d) YES (e) YES, modern as related to trauma (f) NO
Kaufert et al. (1999) End-of-life decision-making among aboriginal Canadians: Interpretation, mediation, and discord in the communication of "bad news"	(a) NO (b) NO (c) YES, indirectly	(d) YES++ (e) MINIMAL (f) NO
Lillie et al. (2020) Culturally adapting an advance care planning communication intervention with American Indian and Alaska Native people in primary care	(a)YES, indirectly (b) NO (c) NO	(d) NO (e) NO (f) NO
Olver et al. (2022) Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: A qualitative study	(a) YES (b) YES, minimal (c) NO	(d) YES (e) YES (f) NO
Rheault et al. (2020) Time to listen: Chronic disease yarning with Aboriginal and Torres Strait Islander peoples living in remote Australia	(a) NO, only mentioned once (b) YES (c) YES, indirectly	(d) YES (e) NO (f) YES

*Note.** (a) building a trusting relationship, (b) historical mistrust, (c) power differentials (d) miscommunication, (e) cultural meaning of disease, (f) low health literacy

Table 7

Profile of Patient Interaction: Categories of Patient Talk as Percentage of Total Patient Communication for the Full Sample



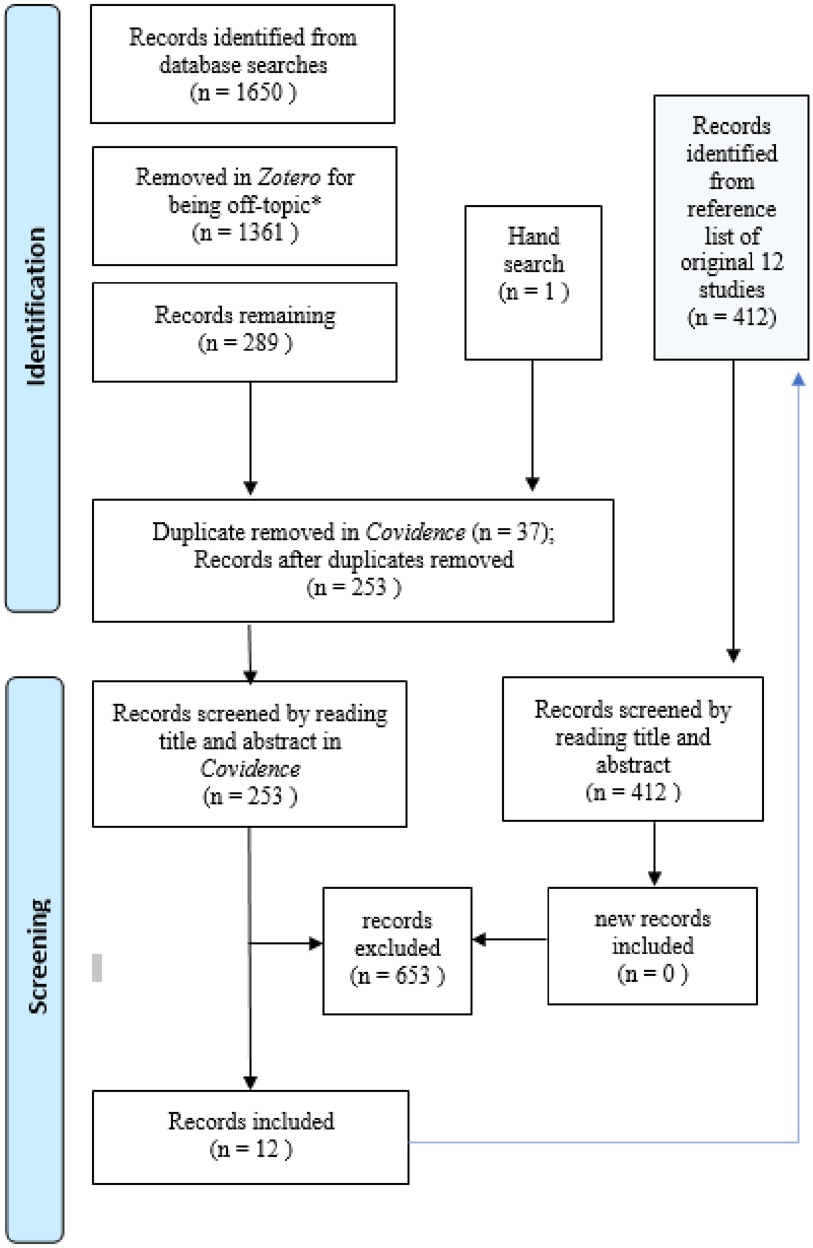
Category of Patient Talk	*Mean % (Standard Deviation)*[a]	*Range of %*
Information giving	52 (12.13)	21-84
Positive talk	32 (11.04)	8-71
Questions	7 (5.11)	0-25
Social talk	4 (5.62)	0-32
Negative talk	4 (3.44)	0-12
Total communication (number of utterances)	134	15-517

a. Percentages do not exactly sum to total utterances because of rounding errors.

Note. The table was copied from Garroutte, E.M., Kunovich, R.M., Buchwald, D., & Goldberg, J. (2006). Medical communication in older American Indians: Variations by ethnic identity. *Journal of Applied Gerontology, 25*(1), 27S–43S. https://doi.org/10.1177/0733464805282725

Figure 1

PRISMA Diagram



Exclusion criteria:
- Not Indigenous population
- Focused on end of life (e.g. actively dying), caregivers, or bereavement
- Focused on documentation
- Focused on symptom or disease management
- Lacked rigour, e.g., opinion piece
- Pediatric population

Inclusion criteria:
- Indigenous population in CA, US, NZ, AUS and/or health care providers working with those Indigenous peoples
- Mentioned exploring relationship between both (a) ACP, palliative care or similar term; and (b) communication (skills) or synonym. Or mentioned SICs, BBN as standalone concept
- EOL, if focused on communication
- Medical communication, if focused on Indigenous populations

* Completely irrelevant results were excluded after reading the title only once (e.g., not English language, perinatal, adoption, suicide, country of India, smoking, etc.)