

## Review Article

# A Qualitative Systematic Review of the Psycho-Oncological Experiences Amongst Global Indigenous Communities

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**Background:** Psycho-oncology is a branch of research related to cancer care that focuses on the psychological, behavioural, spiritual, physical and social aspects of the cancer experience. Whilst psycho-oncology and its applications are relatively nascent, there is a paucity of research regarding the psycho-oncological considerations for Indigenous communities. Due to the deleterious impacts of colonisation, the burden of disease experienced amongst Indigenous Peoples is disproportionately higher than in non-Indigenous populations. Yet, the lack of attention paid towards the development of appropriate models of care fails to reflect this. Therefore, this systematic review aims to build an understanding of psycho-oncology for Indigenous Peoples, globally.

**Methods:** Two independent reviewers searched PubMed, Embase, Web of Science, PsychInfo and ProQuest using a pre-established search strategy. The search was not limited by geographic setting, language, age or gender. Qualitative studies with Indigenous participants that focused on the psychological experiences related to cancer were eligible for inclusion. Included articles were critically appraised using the Joanna Briggs Institute appraisal tool for qualitative studies, and thematic findings were meta-aggregated.

**Results:** The search identified 5632 articles; after screening, a total of 21 studies were included. During the meta-aggregation phase, 11 synthesised findings were identified: structural racism, biomedical health systems, colonisation, shame, fear, loneliness, spiritual pain, loneliness, gratitude, connection, strength and feeling all consumed.

**Conclusion:** There is a need to prioritise and involve Indigenous healthcare workers in all stages of the cancer experience to preserve traditional, cultural and spiritual ways of healing and to deliver culturally responsive healthcare for Indigenous patients.

**Keywords:** cancer; Indigenous health; Indigenous Peoples; psycho-oncology

## 1. Introduction

Emotions inform our behaviour and have a substantial impact on our overall health and well-being. As such, it is just as important to evaluate and monitor emotional aspects related to cancer experiences just as it is standard to routinely monitor cancer patients' physical indicators in order to ensure a holistic treatment plan [1]. A cancer diagnosis can be traumatic for both the patient and family, and the ensuing treatment journey can be overwhelming; thus,

a deep understanding of the psychological perspectives and emotional state of the patient, carer and families is integral to a cancer support plan.

Cobo defines Indigenous communities, peoples and nations as those 'who maintain a historical connection with the land and ways of doing that existed before invasion and colonization. Indigenous peoples are committed to safeguarding, fostering, and passing on to future generations their ancestral lands, along with their cultural identity, which serves as the foundation for their ongoing existence as

Communities' [2]. Colonisation has severely disrupted or exterminated Indigenous Peoples lives at a social, economic, cultural and spiritual level through means such as massacre, displacement, residential schools and forced labour [3]. Therefore, colonisation is recognised as having a fundamental impact on the overall current social educational and health inequality experienced by Indigenous Peoples, as perpetuated by social systems that are inherently racist [4].

Indigenous Peoples' unique connection to culture, family and community cannot be ignored in the treatment of cancer, as the health of an individual is determined by the emotional, cultural, social and physical well-being of their entire community [5]. The Australian National Aboriginal and Torres Strait Islander Cancer Framework specifies that optimal cancer care should be 'person centred so that the whole person (including family and cultural role) is considered, and the psychosocial, cultural and supportive care needs and preferences of Indigenous People are addressed across the continuum of care' [5]. However, most healthcare systems fail to achieve this, due to the lack of acknowledgement and recognition of the role family and community plays in cancer survivorship. The consistent pattern of suboptimal treatment for Indigenous Peoples is reflected in the increased likelihood to be diagnosed with cancer and lower survival rates [6, 7]. This increased disease burden is evidence that on a systemic level, the healthcare system is failing to successfully engage and support the well-being of Indigenous Peoples cancer experience. The disparities in cancer morbidity and mortality between Indigenous and non-Indigenous populations require targeted efforts in colonised countries [8]. It is necessary to explore psychosocial factors related to the experience of cancer for Indigenous Peoples to improve understanding so existing models of care can be re-evaluated and modified in alignment with Indigenous values and needs. To this end, this qualitative systematic review aims to collate psychological experiences of cancer for Indigenous Communities globally.

## 2. Methods

This qualitative systematic review has been registered with the International Prospective Register of Systematic Reviews PROSPERO (CRD42023418335) and the Joanna Briggs Systematic Reviews register. This qualitative systematic review is also reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines statement (Appendix 1). A prior search of PROSPERO and PubMed did not yield any similar studies.

**2.1. Positionality.** It is important for researchers to self-situate due to the influence of researcher subjectivity on the design, analysis and interpretation of research outcomes [9]. This study brings together a team that values the role of lived experiences and strength-based narratives in research related to healthcare for Indigenous Peoples. The primary author is a non-Indigenous Honours student, and the supporting team comprises both Indigenous and non-

Indigenous researchers with extensive experience and involvement in Indigenous health research and qualitative methodologies. The title, abstract screening, appraisal and data extraction were performed by a team of mixed Indigenous and non-Indigenous researchers.

**2.2. Identifying Studies for Inclusion.** A pre-established search strategy which included keywords of 'Indigenous', 'Psychology' and 'Oncology' and their variants was used. The databases screened for identifying eligible literature included PubMed, Embase, Web of Science, PsychInfo, CINAHL and PROQUEST from conception to August 2024. For example, the search strategy used for PubMed Database was as follows: first nation\*[tw] OR "pacific islander"[tw] OR "torres strait islander"[tw] OR aborigin\*[tw] OR aleut\*[tw] OR aymara[tw] OR bushmen[tw] OR chukchi[tw] OR chukotka\*[tw] OR eskimo\*[tw] OR indian\*[tw] OR indigen\*[tw] OR inuit\*[tw] OR inupiaq[tw] OR inupiat[tw] OR khanty[tw] OR maori\*[tw] OR mapuche[tw] OR metis[tw] OR native\*[tw] OR navaho\*[tw] OR navajo\*[tw] OR nenets[tw] OR quechua[tw] OR sami[tw] OR samoan\*[tw] OR tribal[tw] OR tribe\*[tw] OR xingu\*[tw] OR yupik[tw] OR yupik[tw] OR zuni[tw] OR "American Native Continental Ancestry Group"[mh] OR "Native Hawaiian or Other Pacific Islander"[mh] OR "indigenous peoples"[mh], Psych\*[tw] OR Emotion\*[tw], Onco\*[tw] OR Cancer\*[tw] OR Chemo\*[tw]. The search strategy was tailored as per the requirements of the individual databases (Appendix 2).

Search findings from the five databases were exported to Covidence for de-duplicating the search results, management of papers and also screen and shortlist relevant papers. Titles and abstracts were manually screened by two independent reviewers (ES and MC) against the predefined inclusion criteria to discern eligibility and advance to full-text phase of the review. The studies that were included had to be empirical research, qualitative or mixed methods (with clear qualitative illustrations) in design. Studies had to focus on Indigenous experiences, perspectives and psychological aspects of the cancer experience. Where papers contained Indigenous and non-Indigenous participants, they were included if illustrations were attributed to participant's Indigenous status. Publications had to be available in hardcopy or in downloadable form in English, French or Spanish. No geographic or publication date restrictions were placed on studies. Studies that were excluded included quantitative studies, other systematic reviews and conference proceedings, and focused on cancer survivorship and non-Indigenous perspectives on cancer. Any disagreements between the researchers were resolved via group discussion. Although efforts to minimise publication bias have been made, the reviewers are cognisant that the limitation of language could have resulted in the loss of data described in Native languages.

**2.3. Critical Appraisal.** Two independent reviewers (E.S. and M.C.) performed critical appraisal of all the studies using the JBI critical appraisal tool for qualitative studies due to its higher sensitivity to study validity and focus on methodological congruity [10].

**2.4. Data Extraction and Synthesis.** Data extraction was done in two phases. Both phases employed the JBI System for the Unified Management, Assessment and Review of Information (SUMARI) extraction tool [11]. The first phase outlined study characteristics, whilst the second phase entailed comprehensive extraction of data (illustrations and first-person narratives) by the reviewers. Every piece of data was independently reviewed and scored within JBI SUMARI as either 'Unequivocal (U)', 'Credible (C)' or 'Not Supported (NS)'; the ultimate score for each finding was based on inter-reviewer agreement. The final synthesis of findings was achieved manually by transferring all the findings from SUMARI onto a whiteboard and identifying common phrases, concepts and generating categories and ultimately synthesised findings from these.

### 3. Results

The systematic search yielded 5632 articles, of which 1832 were duplicates, resulting in 3820 unique articles eligible to screen for inclusion. After title and abstract screening, 147 texts were retrieved for full-text review; during this phase, 127 studies were excluded, primarily due to study design. A total of 21 studies were included in this qualitative systematic review (Figure 1). The inter-reviewer score from the critical appraisal had a mean of 7.52 and studies performed well across most indicators except for researcher influence and the lack of statements locating the researcher(s) culturally and theoretically (Appendix 3).

**3.1. Study Characteristics.** The included papers were published between 1996 and 2025 (September). Four studies were from Australia [12–15], 10 from the United States of America [16–25], two from Canada [26, 27], three from New Zealand [28–30] and one from Samoa [31] (Table 1). Included studies ranged in study design which included secondary qualitative analysis [12], qualitative descriptive study [16, 22, 24], phenomenological study [17, 19], qualitative thematic analysis [13, 18, 20, 23, 28, 29], patient-oriented qualitative study [26], photovoice [27] and ethnography [21, 25]. Indigenous peoples included from these studies represent Aboriginal and Torres Strait Islander communities [12–15], American Indian and Alaska Native communities [16, 18, 20–25], Native Hawaiian communities [17, 19], First Nations and Inuit communities [26], Samoan [31] and Māori communities [28–30].

**3.2. Synthesised Findings.** From 253 illustrations, 48 categories were generated and aggregated into 11 synthesised findings (Appendix 4). These 11 synthesised findings encompass structural racism, biomedical health systems, colonisation, shame, fear, connection, strength, spiritual pain, loneliness, gratitude and feeling all consumed. From these findings, a conceptual model was developed (Figure 2) to visually represent the psycho-oncological factors related to the cancer journey for Indigenous Peoples, which depicts a landscape that reflects the strong cultural relationship between peoples, communities and land.

**3.3. Structural Landscape.** Three factors at a structural level provided the backdrop for the experience of cancer for Indigenous Peoples, including colonisation [18, 23, 26], racism [18, 20, 27] and biomedical health systems [13, 14, 18–20, 23, 26–30]. These factors are embedded deep within all struggles and battles faced by an Indigenous person.

Colonisation [18, 23, 26] has created mistrust in Western healthcare systems as well as environmental changes related to colonial development that has impacted cancer incidence, such as polluted water [23], fast-food diets and modernisation of society [18]. Reflecting mistrust, an Anishinaabe community member shared the ways in which colonisation has prevented transmission of Indigenous knowledges: *'The Elders told me that there were ways of preventing cancer. They also said that medicine people knew how to cure cancer, however, this highly regarded knowledge has not been passed on to the next generation. Christian authority and the Canadian law prevented First Nations People from assembling to feast, dance or perform ceremonies. Traditional gatherings where knowledge was passed from the Elders and medicine people to the younger generation ceased to take place. . . Many healers suppressed their medical knowledge fearing retribution and persecution from the church and Canadian government. During the decades when it was illegal to practice traditional ceremonies, many of the medicine people, who possessed the knowledge to cure cancer, died [23]'*. Worry about imposed causes of cancer was also identified: *'Food causes cancer. Traditional foods such as wild meat and berries were replaced by foods-of-convenience and foods prepared by frying in fat. Foods-of-convenience include products that are processed, high in fat content, and have preservatives and additives. . . cancer thrive[s] on chemicals in processed food [23]'*.

Structural racism [18, 20, 27] is a repercussion of colonisation and is deeply embedded within institutions, governing structures and policies. For example, healthcare systems continue to disenfranchise Indigenous Peoples by gatekeeping [20] healthcare resources and failing to provide culturally safe care [20, 27]. The included studies highlighted that Indigenous communities were cognisant of the inferior treatment and associated humiliation they experienced. This was illuminated by an American Indian/Alaskan Native Community Member: *'Our prayers and some of our spiritual ways are different from the White society. . . People used to come in the hospital to pray for some of the people. [Providers] would poke fun and say, "Well, whatever, you know, they're going to ring a bell for you, and it's going to heal you." It was very racist [20]'*. Racial profiling induced feelings of alienation for Indigenous patients: *'When I go to the hospital, I have to dress up because I notice, when I dress up, I'm treated differently. . . If I just go in in my blue jeans and T-shirt and my canoe sweatshirt. . . it's immediately drugs [20]'*. A very common experience was the feeling of isolation due to lack of cultural understanding by providers when it came to familial involvement in the cancer experience: *'What they don't understand is that, all these people wanted to come in and visit me. . . and they tell you no. But I tell you what, my family came in. . . when they wanted them to leave, they're not*

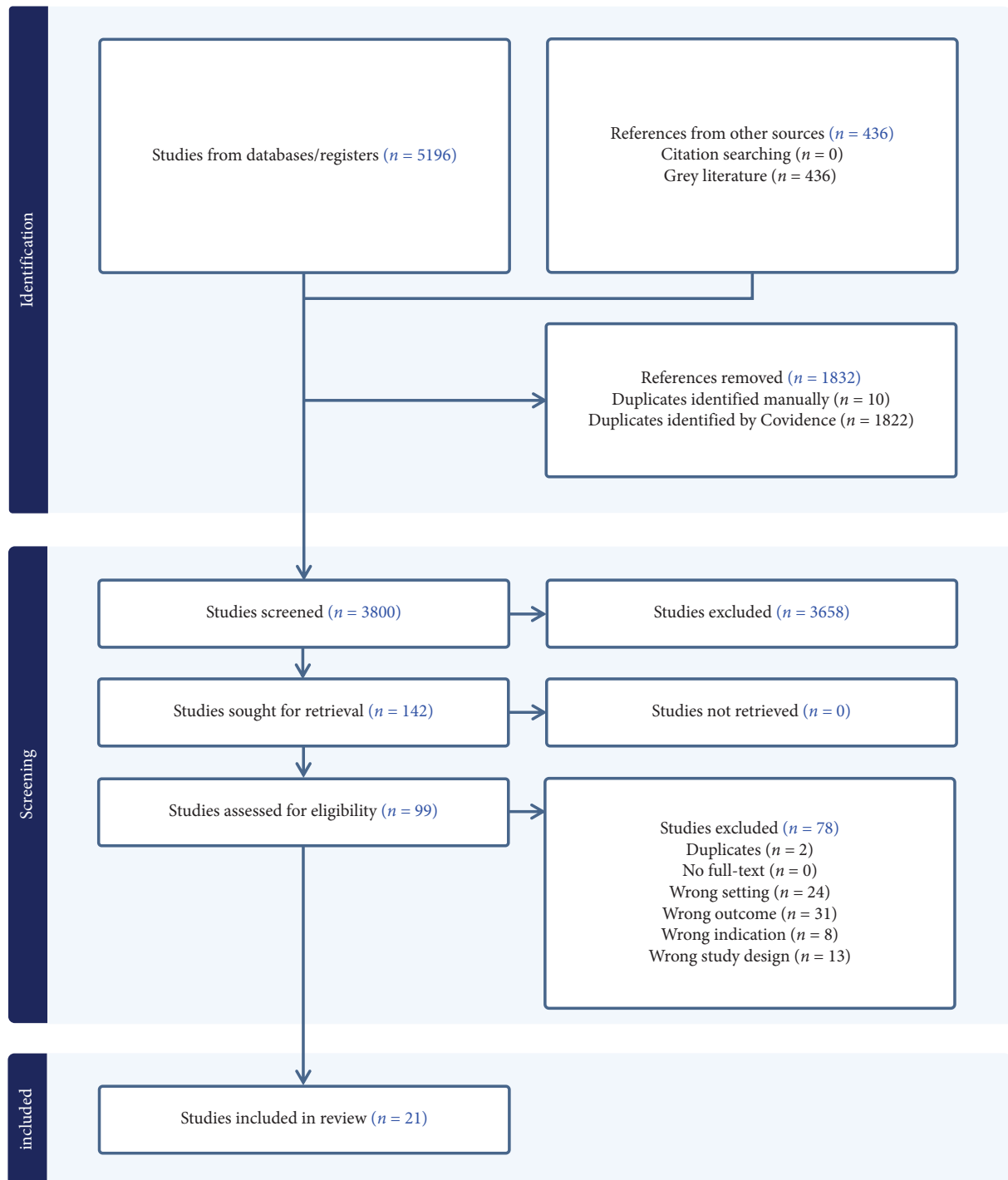


FIGURE 1: PRISMA flow diagram.

*going to leave. That is when the care starts getting really bad because we're there with our family and our friends, and they want to shut them out and not inform them of... what is happening, and that is all what our religious and cultural belief is [20]*'.

Biomedical models of healthcare are underpinned by colonial values which create environments of disregard towards holistic approaches for well-being. This has resulted in systemic barriers that prevent Indigenous Peoples from

optimising available mainstream health services [12–14, 18–20, 23, 26–28]. A commonality between a lot of community members was their frustration with limited resources [14, 23, 27] as well as poor healthcare worker understanding and support: *'So, I had stitches, and I had staples, and I had a port in. I couldn't move... Everybody was saying, "Call this person, this person," so I have four different providers who were taking care of me, and no one is really being responsible for my pain [20]*'. Another sentiment

TABLE 1: Study characteristics.

| Study                     | Methods for data collection and analysis                                                        | Country     | Phenomena of interest                                                                                                                         | Setting/context/culture                                                                                                                  | Participant characteristics and sample size                                                                                                                                                                                                                                                                 | Description of main results                                                                                                                                                                                                                                                           |
|---------------------------|-------------------------------------------------------------------------------------------------|-------------|-----------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| de Groot et al. 2024 [15] | Online yarning circles followed by analysis utilising an inductive thematic approach.           | Australia   | To amplify the voices of First Nations individuals impacted by cancer and advance the development of a culturally informed care pathway.      | Cancer experts, including First Nations people living well with and after cancer, health professionals, researchers and policy makers    | A total of 44 participants participated—participants self-identified as First Nations people living with and after cancer ( $n = 11$ ), health professionals ( $n = 15$ ) and researchers or policy makers ( $n = 12$ ). Of the total sample, 37% identified as First Nations and 79% identified as female. | Models of survivorship care need to integrate family-centred cancer care to holistically support First Nations people throughout and beyond their cancer journey.                                                                                                                     |
| Every et al. 2024 [31]    | Semi-structured interviews followed by thematic analysis                                        | Samoa       | To investigate the palliative care experiences of Samoan patients with cancer and the impact these experiences have on their quality of life. | Patients with cancer registered with the Samoa Cancer Society, or patients recently discharged from the main tertiary hospital in Samoa. | A total of 19 participants were recruited, females ( $n = 11$ , 57.9%) than males ( $n = 8$ , 42.1%). Participants had an average age of 55 years (range 25–71), with the majority aged 50 or older ( $n = 15$ , 79%) and 68% ( $n = 13$ ).                                                                 | Improving palliative care by improving access to opioids and support for family caregivers. Efforts should be made in harnessing the strengths of Samoan culture, including the strong sense of family and the role of religion, to provide support and care for palliative patients. |
| Perelimi et al. 2025 [30] | Semi-structured interviews (Talanoo) following a general inductive approach to analyse the data | New Zealand | To explore Pacific peoples lived experience of cancer and its treatment in the Auckland setting.                                              | Pacific patients under the Auckland Regional Cancer and Blood Service                                                                    | A total of 10 participants were interviewed, 10 female and three male participants with age ranging from 25 to 71 years                                                                                                                                                                                     | Calls for priority towards reducing barriers to access of care and creating a more culturally safe pathway.                                                                                                                                                                           |
| Williams et al. 2025 [29] | Semi-structured interviews followed by reflexive thematic analysis                              | New Zealand | To explore endometrial cancer survivors' experiences of being offered nutrition and well-being advice.                                        | Pacific, Maori and European ethnicity people who had completed treatment for endometrial cancer in the past 12 months                    | Ethnicity of the participants was Māori ( $n = 5$ ), Pacific Peoples ( $n = 5$ , including Samoan $n = 3$ , Tongan $n = 1$ and Kiribati $n = 1$ ) and NZ European ( $n = 5$ ). Age range was 34–74 years (median = 57 years).                                                                               | A holistic care program could facilitate wider access to nutrition and well-being advice and better meet the needs of this population.                                                                                                                                                |

TABLE 1: Continued.

| Study                      | Methods for data collection and analysis                                                                            | Country          | Phenomena of interest                                                                                                                                              | Setting/context/culture                                                        | Participant characteristics and sample size                                                                                                                                                                                                                                                                                                                         | Description of main results                                                                                                                                                                                                    |
|----------------------------|---------------------------------------------------------------------------------------------------------------------|------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Bernardes et al. 2020 [32] | Mixed methods and interviews<br>- Medical chart review<br>- Hospital patient data<br>- Death Registration Data      | Australia        | Improve our understanding of Indigenous patients' experience and the quality of end-of-life care to identify priority needs of Indigenous Australians with cancer. | Aboriginal and Torres Strait Islander people with cancer at their end of life. | Participant characteristics: had a cancer diagnosis, were indigenous Australian, aged $\geq 18$ years and able to understand English<br>Sample size: 248 adult Indigenous people; 58 participants died (23%) during the period of data via linkage and were included in this analysis.                                                                              | 48% did not report any unmet needs, 17% worried about the treatment results, 16% money worries and 16% anxiety<br>Utilisation of palliative care services that manage a full range of physical and psychosocial needs was low. |
| Burnette et al. 2021 [16]  | Semi-structured interviews<br>Analysis—qualitative descriptive analysis—identifying core concepts and themes.       | USA              | What factors promote and undermine the resilience of Indigenous women who experience cancer?                                                                       | American Indian and Alaska natives in the USA                                  | Participant characteristics: Indigenous women from the Northern Plains region of the U.S. Inclusion criteria were (a) having any type of cancer within 10 years of data collection; (b) No recurrence of cancer symptoms and completion of treatment regimen; (c) being female, self-identifying as Indigenous; and (d) residing in South Dakota<br>Sample size: 43 | 88% of participants indicated personal growth in response to having cancer                                                                                                                                                     |
| Calumet 2017 [17]          | Demographic study, interviews<br>Analysis—qualitative study. NVivo 11 using Word cloud to see the most common words | USA (California) | Exploration of the lived experience of Mana'olana/hope in Native Hawaiian women who had been diagnosed with breast cancer.                                         | Native Hawaiian women, Hawaii                                                  | Participant characteristics: Native Hawaiian women with breast cancer, at least 18 years of age<br>Sample size: 15                                                                                                                                                                                                                                                  | Native Hawaiian women gain theological strength by using spiritually based resources (SBR).                                                                                                                                    |

TABLE 1: Continued.

| Study                  | Methods for data collection and analysis                                                      | Country | Phenomena of interest                                                                                                                                      | Setting/context/ culture       | Participant characteristics and sample size                                                                                                             | Description of main results                                                                                                                                                                                                                                                             |
|------------------------|-----------------------------------------------------------------------------------------------|---------|------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Carr et al. 2020 [26]  | Sharing circles<br>Analysis: Narrative analysis                                               | Canada  | Exploration of perceptions and experiences of Indigenous patients with cancer to better understand how trust and worldview influence cancer care decisions | First Nations or Métis, Canada | Participant characteristics: First Nations or Métis<br>Sample size: 14.5 identified as family members.                                                  | Trust included mistrust with diagnosis and Western treatment after cancer therapy, protection of Indigenous medicine and physician expertise with treatment recommendations.<br>Worldview was connected to spiritual beliefs, being strong for family and knowing Indigenous survivors. |
| Craft et al. 2017 [18] | Semi-structured interviews<br>Analysis—interpretive descriptive qualitative thematic analysis | USA     | Examination of the experience of living with cancer of American Indians (AIs) in Oklahoma to gain greater understanding of QOL issues.                     | American Indians in Oklahoma   | Participant characteristics: AIs diagnosed with cancer. Women and men older than 18 years<br>Sample size: 20—but only 10 completed follow-up interviews | Care navigation and social support are important aspects to address in intervention development.                                                                                                                                                                                        |

TABLE 1: Continued.

| Study                 | Methods for data collection and analysis                                                                                            | Country                | Phenomena of interest                                                                                                                                     | Setting/context/culture                 | Participant characteristics and sample size                                                                                                                                                                                            | Description of main results                                                                                                                                                                                                                                                                                                                                                                                                                               |
|-----------------------|-------------------------------------------------------------------------------------------------------------------------------------|------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Egan et al. 2016 [28] | Semi-structured interviews<br>Analysis—Generic qualitative analysis                                                                 | New Zealand (Aotearoa) | To explore the coping and support mechanisms people adopt to help understand and manage their cancer experience                                           | New Zealand (Aotearoa) cancer survivors | Participant characteristics:<br>Cancer survivors in the lower half of the North Island, New Zealand (NZ). 15 Māori, 18 European/Pākehā, 4 Pacific and 1 Asian (Korean). Ages ranged from 18 to 88. 27 women, 11 men<br>Sample size: 38 | Seven distinct themes were classified under the overarching theme of empowerment: attitude, change, family/whānau and friends, healthcare and professionals and services, sources of support, employment and tangata whenua (NZ's Indigenous peoples).<br>'One-size-fits-all' approach has its limitations.<br>The importance of drawing on traditional culture and practices throughout the cancer journey was strongly emphasised by Māori participants |
| Eide 2006 [19]        | Descriptive design involving individual participant interviews<br>Analysis: transcribed—reviewed for commonalities and similarities | USA                    | Examination of the lived experience of a selected group of Native Hawaiian breast cancer survivors to help plan future health promotion outreach efforts. | Native Hawaiian women                   | Participant characteristics:<br>Native Hawaiian women living through and beyond a diagnosis of breast cancer, ranging from 44 to 82 years of age.<br>Sample size: 11                                                                   | Themes included the importance of spiritual connection, an altruistic desire to reach out and assist others in a similar situation and a context of familial silence about cancer history. These elements can assist in formulating health promotion and intervention activities for this population.                                                                                                                                                     |

TABLE 1: Continued.

| Study                       | Methods for data collection and analysis                                                                                                             | Country | Phenomena of interest                                                                                                                                                                                        | Setting/context/culture                                                                                   | Participant characteristics and sample size                                                                                                                                                         | Description of main results                                                                                                                                                                                                                                                                                                           |
|-----------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|---------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Haozous et al. 2016 [20]    | Focus groups and semi-structured qualitative interviews<br>Analysis: thematic analysis                                                               | USA     | To describe the experiences of American Indian and Alaska Native cancer survivors to improve understanding of the trajectory of cancer treatment.                                                            | Rural and geographically isolated American Indian and Alaska Native communities in the Pacific Northwest. | Participant characteristics: American Indian and Alaska Native cancer survivors or caregivers in the Pacific Northwest<br>Sample size: 30                                                           | A conceptual model of the cancer experience called Rough Water described participants cancer experience as a collective journey involving family and friends and requiring resources to offset challenges along the way. Dominant themes were delays, isolation, communication, money, advocacy, spirituality and family involvement. |
| Haozous and Knobf 2013 [21] | Ethnographic interviews; semi-structured—questionnaires<br>Brief Pain Inventory-Short Form (BPI-SF)<br>Analysis: descriptive qualitative methodology | USA     | To describe the experience of cancer pain in a southwestern population of American Indians (AIs) and explore the insights and perspectives of health care providers related to the management of cancer pain | American Indians in New Mexico                                                                            | Participant characteristics: American Indian patients and healthcare providers, caregivers and community member all aged 21 years or older<br>Sample size: 13 patients and 11 healthcare providers. | Barriers to pain control amongst AIs included difficulties describing pain, a belief that cancer pain is inevitable and untreatable, and an aversion to taking opioid pain medication. The inability to participate in spiritual and cultural activities caused AIs distress.                                                         |

TABLE 1: Continued.

| Study                        | Methods for data collection and analysis                                                            | Country   | Phenomena of interest                                                                                                                                                                                  | Setting/context/culture                                      | Participant characteristics and sample size                                                                                                               | Description of main results                                                                                                                                                                                                                                                                                                                                  |
|------------------------------|-----------------------------------------------------------------------------------------------------|-----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Haozous et al. 2011 [22]     | Semi-structured interviews. Brief Pain Inventory-Short Form. Analysis—qualitative descriptive study | USA       | To explore the experience of cancer pain in American Indians (AI) from the Northern Plains region of the United States                                                                                 | American Indians in the Northern Plains region               | Participant characteristics: Northern Plains American Indians aged 31–75 years<br>Sample size: 10                                                         | Participants reported mild-to-moderate pain on a daily basis, and pain negatively interfered with their daily activities and enjoyment of life.<br>Participants reported psychosocial distress through feelings of guilt, depression and isolation related to their cancer, and they relied strongly on prayer and traditional medicine in coping with pain. |
| Hart-Wasekeesikaw, 1996 [23] | Semi-structured interview<br>Analysis: descriptive, ethnographic study                              | USA       | To explore the experiences of First Nations People diagnosed with cancer and Elders' perceptions of cancer                                                                                             | First Nations People (Anishinaabe communities)               | Participant characteristics: First Nations people living in four Anishinaabe communities, diagnosed with cancer and 18 years or older.<br>Sample size: 46 | Informants suggested that Western medicine is limited in its ability to cure cancer.<br>Spiritual visions and dreams were important to First Nations People.                                                                                                                                                                                                 |
| Meiklejohn et al. 2019 [13]  | Photovoice<br>Analysis: thematic analysis                                                           | Australia | Aims to make community perceptions of cancer visible, facilitate development of resources representing these perceptions and briefly evaluate the project from the Indigenous community's perspective. | Indigenous Australians in a regional community in Queensland | Participant characteristics: Any consenting community member aged 18 years and older<br>Sample size                                                       | Three main themes were identified by participants as important to improving cancer outcomes: (1) silence in the community, (2) support is important or survivorship, (3) awareness of cancer and the importance of sharing positive stories.                                                                                                                 |

TABLE 1: Continued.

| Study                           | Methods for data collection and analysis                                                                          | Country            | Phenomena of interest                                                                                                    | Setting/context/culture                                                             | Participant characteristics and sample size                                                                                                                                                | Description of main results                                                                                                                                                                                                                                                                                                                                                                           |
|---------------------------------|-------------------------------------------------------------------------------------------------------------------|--------------------|--------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Poudrier and Mac-Lean 2009 [27] | Interview and photovoice<br>Analysis: through a feminist visibility and postcolonial lens (decolonising approach) | Canada             | To explore and to begin to make visible Aboriginal women's experiences with breast cancer using photovoice.              | Aboriginal women who had completed breast cancer treatment in Saskatchewan, Canada. | Participant characteristics:<br>Aboriginal women residing in Saskatchewan who had completed breast cancer treatment, ranging in ages 42–75<br>Sample size: 12                              | There is a need for multidimensional support which reflects, and makes visible, the lived realities of Aboriginal women in three areas: (i) Aboriginal women's support systems; (ii) respectful encounters with healthcare professionals; and (iii) the ongoing availability of information that recognizes their socio-historical and structural position in the context of colonial marginalisation |
| Roh et al. 2018 [24]            | Semi-structured qualitative interview<br>Analysis: NVivo                                                          | USA (South Dakota) | Exploration of the spiritual coping and experience of cancer in American Indian women.                                   | Native American/American Indian (AI) women in the state of South Dakota.            | Participant characteristics:<br>American Indian women cancer survivors ( $n = 14$ breast cancer, $n = 14$ cervical cancer and $n = 15$ colon and other types of cancer)<br>Sample size: 43 | Results indicate that most women drew great comfort, strength, hope and relief from their spiritual and faith traditions, indicating that religious and spiritual practices may be an important protective factor against the strain of the cancer experience                                                                                                                                         |
| St. Clair, 2005 [25]            | Commentary on spirituality life as an active participant recovery                                                 | USA                | Explanation of spirituality and how it is an integral part of recovering, healing and rejoicing in the cancer experience | American Indians in the USA: Cherokee and Eastern Shoshone                          | Author characteristics:<br>American Indians in the USA of Cherokee and Eastern Shoshone background<br>Sample size: 1                                                                       | Spirituality is a key component to healing<br>Through the cancer experience, an individual evaluates one's path in life, thus establishing harmony and balance                                                                                                                                                                                                                                        |

TABLE 1: Continued.

| Study             | Methods for data collection and analysis                               | Country   | Phenomena of interest                                                                                                                                              | Setting/context/culture                                                    | Participant characteristics and sample size                                                                                                                                          | Description of main results                                                                                                                                                                                                                                    |
|-------------------|------------------------------------------------------------------------|-----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Garvey, 2015 [14] | Face-to-face interviews, focus groups<br>Analysis—qualitative research | Australia | To identify the psychosocial aspects of cancer for Indigenous patients, and to validate the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) | Aboriginal and Torres Strait Islanders (Indigenous Australians)—Queensland | Participant characteristics: Aboriginal and Torres Strait Islanders (Indigenous Australians) in Queensland Hospitalised or attending a hospital outpatient clinic<br>Sample size: 29 | Current supportive care needs tools do not meet the needs of Indigenous people with cancer with regard to factors such as language, culture and customs.<br>The SCNAT-IP improves acceptability, relevance and face validity for Indigenous-specific concerns. |

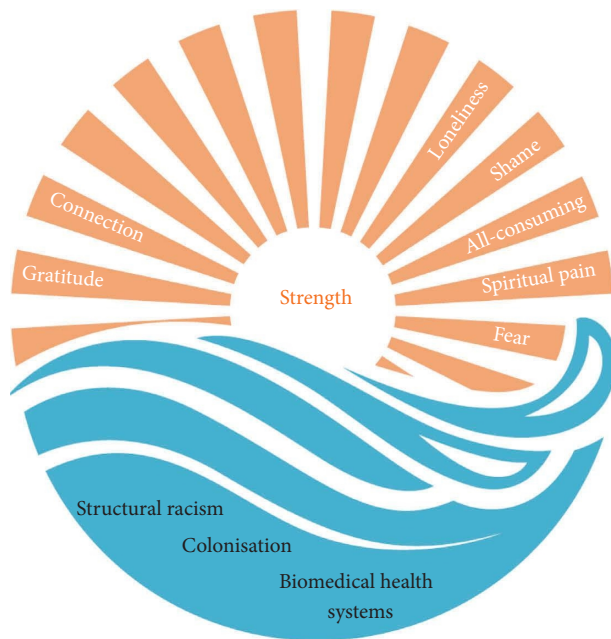


FIGURE 2: Conceptual model.

expressed by community members was their confusion during cancer diagnosis due to the absence of culturally safe communication and knowledge sharing [14, 18, 20, 23, 26, 27] that was often exacerbated by complicated biomedical concepts [23, 28], and feelings of patient disempowerment: *'The surgeon who speaks to you, the doctors, the medicines you're taking—the words they use are commonplace in their daily life. But in ours, they're not [27]'*.

**3.4. The Psycho-Oncological Journey.** Participants experienced feelings of shame [12, 22, 23], fear [12, 13, 19, 27], connection [11, 12, 16, 18, 19, 23, 26, 27], spiritual pain [18, 22, 28], loneliness [19, 22, 23], gratitude [16, 18, 19, 28] and overwhelm [11, 13, 16–21, 24, 26] during their cancer journey against the backdrop of a negative structural landscape.

Perceptions of shame [12, 22, 23] surrounding cancer and diagnosis were common such as community-level stigma of medication misuse where participants felt judged for their medication use by community and family who did not trust that opioids were appropriate for cancer treatment [21]. Community members harboured feelings of shame when engaging with health services due to the invasive nature of some preventative health checks [12, 23] and low privacy in small communities [22]: *'Here on this reservation you can't just talk to anybody, because they really like to talk. They backstab you'*. Shame was also a result of perceived lack of independence when utilising healthcare resources, which resulted in low use of services: *'I don't know if it's because I [feel] ashamed to go to the doctors. . . we'd have to be half dead in bed, do you know what I mean? [12]'*.

Participants repeatedly emphasised that cancer evoked fear or was synonymous with dying [12, 13, 19, 27], usually due to witnessing multiple family members lose their battle

with cancer: *'Once they hear cancer they automatically get frightened and give up hope and people who've lost family members don't want to talk about how it affects them [13]'*.

Loneliness was another emotion related to community and family isolation due to cancer stigma [19, 22, 23], fear or lack of understanding of the cancer experience [14, 21, 22], as expressed by a community member: *'I rub myself[self-massaging]. You know, it kind of goes away a little bit when I do that. But I only do that in the confines of my room because I don't want people to see me doing that because they might think I'm going off my rocker or something [22]'*. Many also cited self-imposed isolation to avoid becoming a burden on their community: *'Some days [the pain] gets worse and then my legs get numb on one side. And sometimes it gets so bad that my arm gets numb. I don't like to tell that I'm not feeling very good. I don't like to complain. I don't want people to think [I'm] sick I just like to try to ignore but sometimes I can't help it so I do a lot of rest and I notice that pain is, sharp pain comes out [23]'*.

For those represented in the included studies, spiritual pain manifested in multiple ways. For some, cancer brought about depression [18, 22, 28] as described by a Māori community member: *'It was, ah, soul sucking. . . It really did sink me into a, deep depression and if anything I can learn from that is that that's probably what I could [have] paid a lot more, ah attention to in terms of seeking a lot more help around that [28]'*. Whilst for others, spiritual pain stemmed from a lack of congruity between Indigenous cultures and mainstream healthcare models, particularly the lack of understanding and accommodation of traditions in the cancer journey [12, 20]. Spiritual pain was associated with guilt and separation from culture for some: *'Spiritual pain it's a really hard setback, especially for me. When I wasn't living here [in Community], because I didn't go to participate in my spiritual ways, like that's why I have spiritual pain. The spiritual part praying and being Native American and I pray to my Creator and ask him for help I don't get what I want and I start blaming: Why did you create me just to watch me suffer? Do you really love us as your children? As your creation? You start questioning your spirituality [20]'*.

Connection whether through community [13, 17] or family support [12, 13, 17, 19, 20, 24, 27, 28] was extremely important in balancing psycho-oncological impacts of cancer. Eight [12, 13, 17, 19, 20, 24, 27, 28] of the 16 included studies highlighted the collective nature of Indigenous communities; which facilitated both emotional and practical assistance during one's cancer journey: *'It really helped my prayer, with the healing ceremonies and knowing that I had that type of support from family that were doing the ceremonies for me—that I knew that I had that support and the prayers were there for me and that helped me get through with the diagnosis and just getting through the whole ordeal [24]'*.

Participants expressed how the multifaceted aspects of cancer had positive impacts on their life, citing gratitude for cancer as a catalyst for family reconnection [16, 18, 19, 28] and a desire to appreciate and cherish life [16, 17]. An American Indian Community member described the change cancer has had on their life: *'Your life changes drastically when you're diagnosed with cancer. And I think*

people start living for that moment, you know, every day. And I have to be thankful every day. I don't have time to be sad about my life [16]'. Furthermore, the cancer experience also encouraged participants to help others through their pain and share their knowledge: *'It impacted me hard. I mean like I said I was to where I wanted to die because my mom was dying so I didn't care if I died. But then I thought about my kids and I thought about my grandkids so I wanted it out and I wanted it gone forever so I didn't have to think about it after I lost my mom after I went through all that with her. I didn't want to have cancer and I tried to talk to other young girls or woman who have it and try to uplift them. Some of them don't even go to church. Some of them don't even know our Lakota way of life. They don't even know the sweats [sweat lodges]. They don't know what it means or anything like that. So, I always try to support them in any way I can and ask them if you want to go to sweat? Maybe if we go to sweat we could talk about it [16]'*.

Cancer and its impacts are pervasive, affecting quality of life [14, 20–22] and disrupting normalcy [12, 18, 19, 23, 26, 28], which requires participants to reconcile with an overwhelming amount of change. The inability to participate in traditional ceremonies because of illness highlighted the importance of maintaining cultural traditions to create a semblance of normalcy. One participant illustrated how she tried to embed her cultural practices into treatment routines: *'I did my chores, helped my husband. I still worked on the ranch with him. When I would go for my therapy in Kona, I would wear my scarf and then I'd wear my hat with feathers to match whatever I was wearing. Cause that's the way I used to dress when I was working [19]'*. Furthermore, cancer's overwhelming nature often required participants to partake in self-inquiry amidst mental and physical changes from disease: *'I have always been the strong one, and now people have to help me. . . I have always been the rock' [18]*.

Strength was the most dominant synthesised finding, with evidence from 14 of the 16 included studies focussing on the immense strength demonstrated by Indigenous Peoples whilst navigating their cancer journeys [12, 16–19, 22–28]. Overwhelmingly, the crux of these narratives arose from prioritising traditional ways of healing, faith and spirituality to provide reassurance, hope and strength as illustrated by a Māori community member: *'We went home straight away and had karakia [prayer] with my mum and aunty, another elderly kuia that you know is well respected and kind of put it back into perspective because I was yeah a mess and we just went back into her lounge and just sat down and yeah we had karakia and once that had happened I you know I settled down [19]'*. Community members further demonstrated strength through resilience: *'I was probably devastated for about 30s and then 'Give me the facts, the options and get out of my way, because I'm going to get on with it! I know for some it's devastating. [A] lot of Kooris just don't want to be center of attention so part of it's that. Lack of confidence or lack of experience. And the fear of the unknown and not knowing what's round the corner. I'm not big noting myself [but] I really don't give a shit! If I've got cancer, I've got cancer: it's not going to worry me [And] it's not going to stop me from living my life [12]'*.

## 4. Discussion

This systematic review included Indigenous cancer patient perspectives from 16 articles across four countries. Indigenous perspectives gathered from the included studies highlight the systematic barriers in Western models of healthcare, which were underpinned with themes of racism and colonisation. The psycho-oncological aspects of cancer experiences for Indigenous Peoples included feelings of shame, fear, connection, spiritual pain, loneliness, gratitude and all consumed. This review highlighted the centrality of strength in navigating both feelings and systematic barriers for Indigenous Peoples living with cancer.

There needs to be a distinction made between Indigenous and non-Indigenous psycho-oncology and its research due to the cultural context and social circumstances that permeates the Indigenous experience. The differences in healthcare experience within any aspect of the cancer continuum (screening, diagnosis, continuity of care, treatment and survivorship) [33] and the differences in psycho-oncological states between Indigenous and non-Indigenous Peoples can be largely attributed to the historical, political, structural and social determinants of health (e.g., poverty, racism and lack of a culturally responsive and accessible health systems) [34]. These factors influence the ways in which Indigenous Peoples engage with healthcare systems, and provide context for feelings of disorientation, fear, despair and embarrassment when navigating these systems. These feelings can lead to abandoning treatment [35], or as was demonstrated in this review, avoiding preventative screening [23]. An Indigenous person's life, culture and circumstances are not considered within biomedical models of care due to the hegemonic influence of colonial ideologies and the subsequent design of structurally racist services and environments of care provision [36].

**4.1. Clinical Implications.** The impact of psycho-oncological factors on the accessibility of supports and services throughout one's journey has been identified in previous works [33, 37]. Studies included in this review reinforced considerations necessary to understanding and supporting the psycho-oncological journey of Indigenous Peoples living with cancer; this includes spiritual pain, humiliation due to structural racism, fear, feeling all consumed but also strength reclaimed from partaking in communal cultural practices and embracing one's spirituality. Incorporation of psycho-oncological factors identified in this review into provision of cancer care is needed to address the significant disparities in cancer outcomes for Indigenous Peoples and ensure culturally secure and appropriate cancer support and care. Action by service providers at a systemic level is required that embeds cultural security for Indigenous Peoples; otherwise, exclusionary practices of Western healthcare models that are incongruent to the culture and needs of Indigenous Peoples will persist, and inequities will widen. For example, experiences of structural racism and cultural insensitivity in a healthcare setting can be reduced via cultural security training and policies, as well as inclusion of Indigenous

healthcare workers with lived experience and understanding of both Indigenous worldviews and biomedical systems. The latter could manifest in cultural brokage between Indigenous patients and non-Indigenous health specialists, thus mitigating feelings of shame Indigenous Peoples experience [38]. Culturally secure healthcare that works to mitigate the pervasive impact of colonisation in its service provision is exemplified by Indigenous-led health services, including Aboriginal Community Controlled Health Organisations in Australia [39], the National Collaborating Centre for Indigenous Health in Canada [40] and whanau (family and Community)-centred initiatives in Aotearoa New Zealand [41]. Additionally, culturally appropriate cancer support programs designed and delivered by Indigenous Peoples are needed to provide opportunities for those undergoing treatment to participate in traditional ways of healing and ceremonies. It is important to note that these customs should be culturally specific to each unique context, as Indigenous cultures, practices and knowledges are diverse and rich within and across countries; to generalise strategies for Indigenous Peoples as a whole would be to continue assumptive practices of colonisation and culturally insecure models of care. Ultimately, the importance of Indigenous leadership and involvement throughout the cancer continuum cannot be understated in the pursuit of Indigenous health sovereignty.

**4.2. Study Limitations.** This systematic review is, to the best of our knowledge, the first to conduct a systematic review on the literature pertaining to the psycho-oncology of Indigenous Peoples globally. This review has adhered to all protocols to ensure legitimacy and transparency. Another strength is its broad representation of Indigenous experience through illustrations from several different countries. An innovative strength of this study is also the inclusion of our conceptual model that forms the theoretical framework of this study which in accordance with other studies foregrounds the continuing impact of colonisation and its intergenerational trauma at a systemic level, with our findings indicating a holistic approach that prioritises Indigenous Peoples feelings and experiences is needed to improve community health outcomes.

Limitations include the lack of literature included in Indigenous languages due to the language barrier could have resulted in loss of data and thus additional nuance to our discussion. Future studies should consider incorporating literature written in the Indigenous language of the Indigenous Peoples population being analysed. Furthermore, this review did not include data from local community-controlled clinics that could have also added to our findings.

## 5. Conclusion

Prioritising and involving Indigenous healthcare workers in all stages of the cancer continuum to preserve traditional cultural and spiritual ways of healing is paramount to create a culturally responsive healthcare model for Indigenous patients. There needs to be recognition and acceptance of the

limitations of mainstream healthcare models in meeting the psycho-oncological needs of Indigenous Peoples living with cancer. Only then, can a truly holistic approach be adopted which addresses specific barriers and facilitators, thus adequately addressing the social, emotional and health needs of Indigenous communities.

## Data Availability Statement

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

## Ethics Statement

The authors have nothing to report.

## Conflicts of Interest

The authors declare no conflicts of interest.

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## Supporting Information

Additional supporting information can be found online in the Supporting Information section.

*Supporting Information 1.* Appendix 1: Completed PRISMA checklist.

*Supporting Information 2.* Appendix 2: Detailed search strategy described with logic grid.

*Supporting Information 3.* Appendix 3: Inter-reviewer reliability assessment table.

*Supporting Information 4.* Appendix 4: Synthesised findings from the systematic review.

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