

# The experiences of caregivers of Indigenous cancer survivors in Australia, Canada, New Zealand, and the United States: a systematic review

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## Abstract

**Background:** Caregivers of Indigenous cancer survivors provide critical unpaid support to survivors, yet they rarely receive information or training for this role and may themselves benefit from support services. Little is documented about the experiences of caregivers of Indigenous cancer survivors. The aim of this systematic review was to identify and aggregate qualitative research describing the experiences of caregivers of Indigenous cancer survivors in Australia, New Zealand, Canada and the United States.

**Methods:** We systematically searched PsycINFO, PubMed, CINAHL, Embase, Scopus and Web of Science using keywords relating to Indigenous populations; caregivers; and cancer. Data were extracted from original qualitative research articles published up to March 2020. **Results:** From 24 full-text articles, 14 articles from 13 studies were analyzed using meta-aggregation. This highlighted key caregiver experiences relating to: the need for information about cancer and services; providing and receiving support; communication challenges and responsibilities; balancing caregiver roles and emotions; and culturally unsafe health systems and settings. Caregivers of Indigenous cancer survivors often act as mediator between Western biomedical approaches to cancer care and Indigenous peoples' holistic and family-focused views of health and wellbeing, aiming to ensure that both health professionals and the cancer survivors understand each other's perspectives and preferences for care. Caregivers expressed preferences for family-focussed rather than patient-focussed care. Culturally unsafe health care systems created barriers to optimal care. **Conclusions:** The findings reveal caregivers' unique experiences of caring for an Indigenous cancer survivor, and identifies several unmet needs which should be appropriately and systematically addressed. Caregivers should be regarded as co-clients with their own needs as well as co-workers with health professionals providing cancer care. Ultimately supporting caregivers will contribute to improving health outcomes for Indigenous cancer survivors.

**Keywords:** Caregivers, Indigenous populations, Cancer care, Neoplasms, Qualitative systematic review, Unmet needs

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## Introduction

A cancer diagnosis and cancer treatment can have a significant impact not only on the survivor (defined from the time of diagnosis onward<sup>[1]</sup>), but also on their family, with some family members taking on the role of caregiver.<sup>[2,3]</sup> Caregivers are defined as individuals who provide care to cancer survivors at any time during active treatment, palliative care, or survivorship, and who are not formally employed for the role. Although they commonly assist with illness management, emotional, social and financial support, and daily life responsibilities,<sup>[2]</sup> they are rarely given information, training, or support for this role.<sup>[4]</sup>

Cancer survivors' health care teams often rely on the caregivers to provide care and assistance, when in reality caregivers play the dual role of co-clients and co-workers.<sup>[5]</sup> When family members become caregivers, they often experience caregiver burden as a result of the multiple roles they fulfill and the imbalance of care demands relative to their time, physical and emotional states, and availability of financial and other resources.<sup>[6,7]</sup> Therefore, in many cases, caregivers experience a range of negative effects, such as high levels of uncertainty and psychological burden,<sup>[8-11]</sup> unmet support needs,<sup>[12]</sup> and poor physical and psychological health.<sup>[13,14]</sup>

Understanding the experiences of caregivers of Indigenous cancer survivors is particularly important given Indigenous peoples' poorer cancer outcomes compared to non-Indigenous people.<sup>[15]</sup> Indigenous inequality is a global health problem. In terms of cancer, numerous studies have documented higher mortality and lower survival rates among Indigenous, compared to non-Indigenous, cohorts.<sup>[15-20]</sup> For example, in the United States, the overall cancer death rates increased significantly for American Indians and Alaskan Natives from 1990 to 2009, whereas overall cancer death rates declined significantly for Whites.<sup>[20]</sup> In Australia, the 5-year observed survival rate between 2010 and 2014 for all cancers combined was 48% for Indigenous Australians and 59% for non-Indigenous Australians.<sup>[19]</sup> Indigenous peoples worldwide experience social disadvantage compared to their respective non-Indigenous populations.<sup>[21]</sup> Poverty, racism, and lack of a culturally responsive health system are reported as important contributors to the cancer burden faced by Indigenous peoples.<sup>[22,23]</sup> Aspects of the broader social environment can also influence the way individuals and families engage with health care and manage their own health. The implications of the health and social inequity experienced by Indigenous populations worldwide for caregivers of Indigenous cancer survivors is that Indigenous caregivers may experience additional burden and unmet psychological needs than other caregivers.

Despite the invaluable roles that caregivers perform, there remains a limited understanding of the lived experiences of caregivers of Indigenous peoples with cancer. Insight into these

experiences is essential to developing focused interventions and allocating resources to support them and in turn support the cancer survivor. Accordingly, the objective of this systematic review was to describe the lived experiences of caregivers of Indigenous cancer survivors in Australia, New Zealand, United States, and Canada.

## Methods

Reporting of the review adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.<sup>[24]</sup>

### Inclusion and exclusion criteria

Studies were included if they were published in English, peer-reviewed, and provided original qualitative data that reported the experiences of caregivers (both Indigenous and non-Indigenous) of Indigenous adult cancer survivors from Australia (Aboriginal and Torres Strait Islander people), Canada (Aboriginal, First Nations, Inuit, or Métis people), New Zealand (Māori), or United States (American Indian, Native American, Alaskan Native, Inuit, and Native Hawaiian people). All eligible articles were included in the review regardless of quality assessment rating.

Studies were excluded if the data of caregivers of Indigenous survivors were not reported separately to caregivers of non-Indigenous survivors, if no qualitative research methods were employed, and if reports of caregiver experiences came from another party (eg, the cancer survivor or a health professional). Reviews, research theses, conference abstracts and presentations, protocol papers, books, and editorials were also excluded.

### Information sources and search strategy

The electronic databases PsycINFO, PubMed, Embase, Scopus, Web of Science, and CINAHL were searched using a combination of free-text keywords and Medical Subject Headings (MeSH) or other controlled vocabulary (see Table 1 for example search and Supplemental Digital Content, Table 1, <http://links.lww.com/OR9/A18> for the full search strategy). Searches were limited to studies conducted with humans from the database inception to January 2019. The search was updated in March 2020.

### Study selection

After removing duplicates, 2 reviewers (AM and HMB, non-Indigenous researchers) independently screened article titles and abstracts using the Rayyan systematic review software.<sup>[25]</sup> AM and HMB conducted independent full-text review according to inclusion and exclusion criteria with discrepancies resolved

**Table 1**

**Free text terms for all databases and controlled vocabulary for PsycINFO.**

	Title or abstract free-text terms	Controlled vocabulary
Indigenous population terms	[Indigenous OR Aborigin* OR "Torres Strait Islander*" OR "Torres Strait" OR "Indigenous population" OR "First nation*" OR "American Indian*" OR Inuit* OR metis OR Maori* OR "Native American" OR "Alaska* Native*" OR "Native Hawaiian*" OR Eskimo*]	"Indigenous populations"
Caregivers search terms	[carer* OR caregiv* OR "support person" OR "support people" OR "support*" OR "care team*" OR Family care OR Family caregiv*]	"Home Care" OR "Caregiver burden" OR "Caregivers" OR "Caring Behaviors" OR "Caring Behaviours"
Cancer terms	[cancer* OR neoplasm*]	"Neoplasms"

through discussion. Studies that met all criteria were retained for inclusion and their reference lists searched to identify additional relevant articles. If the title appeared relevant to the aims of the systematic review, AM and HMB followed an identical process of title and abstract screening as articles found via database searches. No additional articles were found through reference list searches.

### Data extraction and analysis

Three authors (AM, HMB, and TB, an Aboriginal researcher) independently piloted the data extraction approach on two articles to ensure consistency. After reaching consensus, 2 authors (AM and HMB) conducted double independent data extraction for the remaining articles, meeting regularly to resolve conflicts. Discrepancies were resolved by TB. When necessary, corresponding authors were contacted to clarify participant details.

Data extracted were: study location, design, sample size, demographic details of caregivers and cancer survivors, and details of survivors' cancer diagnosis and stage. Qualitative data extracted were verbatim sections of text describing caregivers' experiences, which were analyzed using meta-aggregation. Verbatim quotes were organized into categories, which in turn were organized into synthesized findings consisting of at least 2 categories. This approach avoids reinterpretation of data and presents the findings of the articles while maintaining the intent of the original authors.<sup>[26]</sup> AM, HMB, and TB conducted the initial meta-aggregation, developing several versions; GG (an Aboriginal researcher) provided feedback to produce the final meta-aggregation structure which is presented in the Results.

Finally, we developed a list of implied unmet needs of caregivers of Indigenous cancer survivors extrapolated from the findings of the analysis. These were developed by examining caregivers' experiences and suggesting any associated needs that were unmet or required further support.

### Quality assessment

The quality of evidence was assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research.<sup>[27]</sup> Although this tool does not itself provide a scoring system, we used a scoring system similar to that used in other studies using this tool.<sup>[28]</sup> Possible scores for each item were: 0 (item not addressed), 1 (item partially addressed or poorly addressed), or 2 (item completely addressed). There were 10 items covering a range of topics such as research design, recruitment, reflexivity of researchers, ethical issues, and data analysis. AM, HMB, and TB conducted independent quality assessment on all included articles, then discussed scores and resolved discrepancies. All articles were assigned a quality assessment score in the form of a percentage.

### Search update

Database searches were re-run in March 2020. HMB and TB independently screened newly identified titles and abstracts and conducted full-text review, data extraction, and quality assessment, following the procedure described above. GG reviewed the updated results and confirmed that the new data did not change the meta-aggregation findings.

## Results

As shown in Figure 1, 14 articles from 13 distinct studies met inclusion criteria.

### Characteristics of included studies

As shown in Table 2, most research was conducted in Australia (n=6) and United States (n=5), followed by New Zealand (n=2) and Canada (n=1). The Indigenous groups represented in the articles were Aboriginal Australians; Torres Strait Islanders; Native Hawaiians; American Indians; Alaskan Natives; Māori; and First Nations of Canada (terminology reflects the terms used in the original articles). Only 2 studies reported findings from caregivers exclusively.<sup>[29,30]</sup> The majority of studies focused on cancer survivors' experiences, using caregiver views to augment cancer survivors' stories.

Caregivers were typically family members of Indigenous cancer survivors, and predominantly female. The Indigenous status of the caregivers was not consistently reported, but where this information was provided, most caregivers identified as being Indigenous. The articles did not systematically separate findings for Indigenous and non-Indigenous caregivers. Caregivers provided support to survivors with a range of cancer types; however, cancers of the breast, colon, and prostate were most frequently reported. Stage of the survivors' cancer was rarely reported. Quality assessment ratings ranged from 70% to 95%.

### Meta-aggregation findings

Five synthesized findings emerged from the meta-aggregation process (Table 3): need for information about cancer and services; providing and receiving support; communication challenges and responsibilities; balancing caregiver roles and emotions; and culturally unsafe health systems and settings. For ease of reading, each category has been summarized under the synthesized finding. The complete meta-aggregation table can be found in Supplemental Digital Content, Table 2, <http://links.lww.com/OR9/A19>.

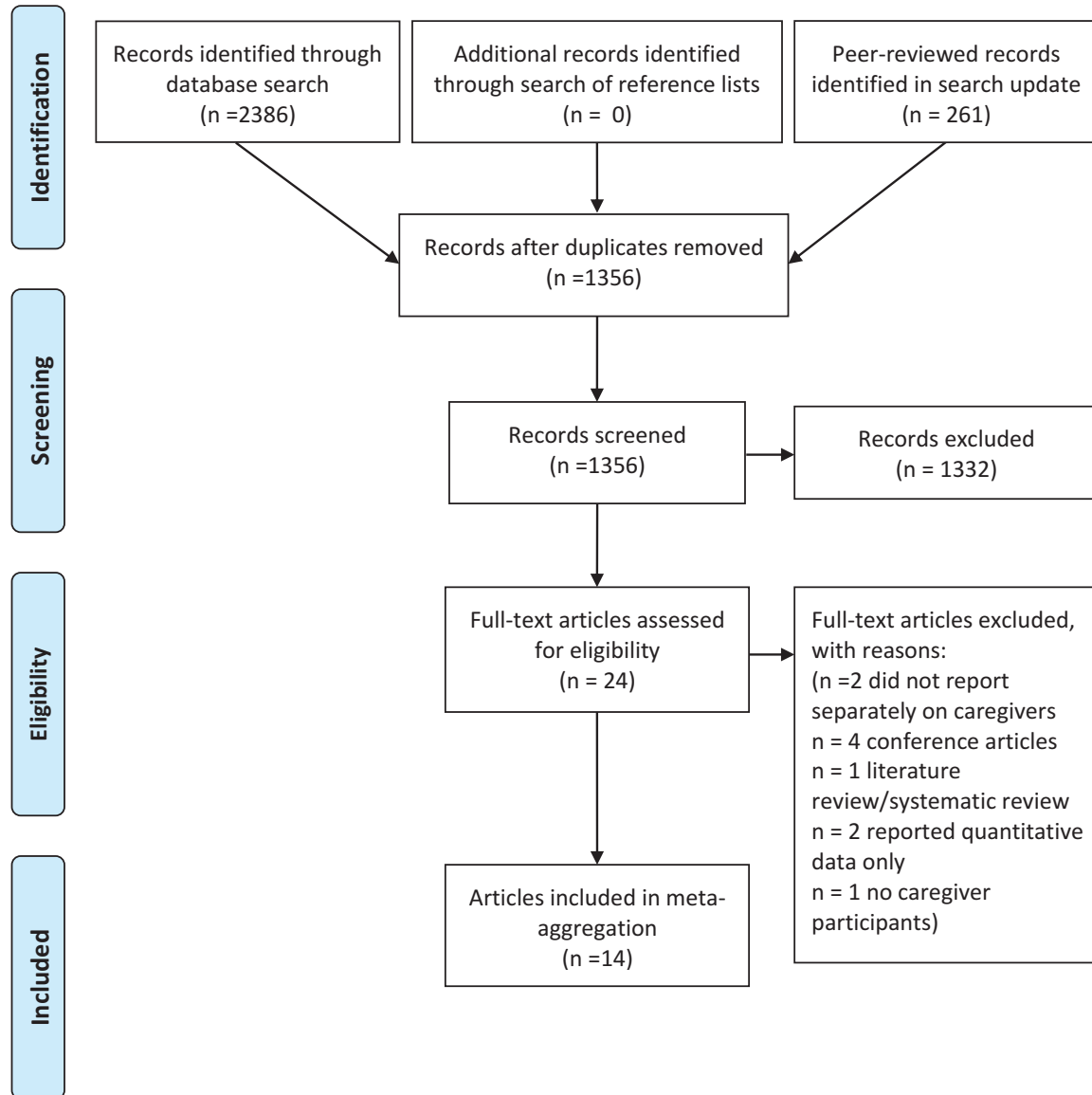
### Need for information about cancer and services

Caregivers had limited knowledge, experience of, or expectations about cancer before the patient receiving their diagnosis.<sup>[31-34]</sup> Culturally unsafe health care contributed to barriers to information seeking, described in a later section. Indigenous views and cultural beliefs about the origins of cancer needed to be considered in providing information about cancer to caregivers. For example, some caregivers viewed cancer as taboo or curse with one caregiver believing that cancer was a curse as punishment for a previous transgression:

*“Aboriginal people have this notion of being sung... it's basically a bad magic put on somebody . . . it was almost like you deserved it...”*<sup>[33, p132]</sup> (Aboriginal Australian)

Caregivers described “cycles of silence”<sup>[35]</sup> among families and communities that perpetuated gaps in knowledge about cancer and inhibited open discussion within the community.<sup>[30,34,35]</sup>

Caregivers often acquired information about support services through family and peer networks in an ad hoc fashion.<sup>[36]</sup> They were often unfamiliar with financial aid programs (eg, transport and hospice services) and how to engage these services, which



**Figure 1.** PRISMA flowchart displaying article selection (adapted from Moher et al., 2009).

caused confusion.<sup>[30,36,37]</sup> Some caregivers reported stigma associated with using these services.<sup>[37]</sup>

Caregivers expressed a need for greater availability of information for Indigenous communities about cancer and its signs and symptoms, particularly in the context of other competing health priorities:

*“There’s no information session at the ground roots, on the reserves and that to speak to people...we had all these information sessions, but I don’t think we had one on cancer. . . .”*<sup>34, p. 660</sup> (Aboriginal Australian).

Caregivers wanted knowledge about a range of topics, including cancer signs and symptoms, treatment options, navigating the healthcare system, and caregiving skills. They preferred to receive this information via brochures, education programs, and family counseling.<sup>[32,34]</sup>

### **Providing and receiving support**

Caregivers provided emotional, spiritual, practical, financial and cultural support to the survivor. Caregivers reported feeling emotionally supported by healthcare professionals when they demonstrated empathy and kindness.<sup>[31]</sup> Caregivers described seeking emotional and spiritual support through support groups and prayer.<sup>[29,38]</sup> Peer support groups offered the opportunity to discuss shared lived experiences with other caregivers.<sup>[38]</sup> As reflected by a Native Hawaiian participant’s comment:

*“We all suffering da same”*<sup>38, p. 330</sup> (Native Hawaiian).

A Māori caregiver reported the importance of spirituality through the ritual of nightly prayer that brought the family together:

*“ . . . The whole family would go in [Mum’s room] and pray and talk to God and sing. Then all the children would kiss*

**Table 2**  
**Characteristics of Included Studies.**

Author, year	Setting	Indigenous population	Entire sample size (caregiver sample size)	Sample of Indigenous caregivers	Survivors' cancer type and stage	Caregivers' relationship to indigenous survivor	Age of caregivers: mean/range	Sex of caregivers	Quality appraisal rating
<b>Australia</b> Meiklejohn et al. (2019) <sup>[40]</sup> Reilly et al. 2018 <sup>[38]</sup>	Small regional town in Queensland Hospital and community health services in urban (42%), regional (18%) and remote (40%) areas in South Australia	Aboriginal and Torres Strait Islander Australians Aboriginal Australians	Approximately 61 (NR) 62 (11)	NR 11	NR Cancers of the respiratory system, gastrointestinal system, breast, head and neck, reproductive organs, leukemia and lymphoma, and others. Stage NR	NR Family member NFS	18+, NFS NCB	NR 4 Males, 7 females	80% 80%
Shahid et al. 2009 <sup>[33]</sup> Thompson et al. 2011 <sup>[41]</sup> Treloar et al. 2013 <sup>[34]</sup>	Urban and regional Aboriginal Health Services in Western Australia Community sample from urban and rural services in Western Australia AMS, hospital oncology services, palliative care facilities and personal networks in eastern New South Wales	Aboriginal Australians Aboriginal Australians Aboriginal Australians	37 (16) 30 (16) 56 (18)	16 15 14	NR NR NR	Family member NFS Family member NFS 8x children 5x spouse/partner 2x parent 1x sibling 2x caring for >1 family member with cancer	NCB NR NCB	NCB NCB 2 Males, 16 females	75% 80% 95%
Treloar et al. 2014 <sup>[36]</sup>	AMS, hospital oncology services, palliative care facilities and personal networks in eastern New South Wales	Aboriginal Australians	56 (18)	14	NR	8x children 5x spouse/partner 2x parent 1x sibling 2x caring for >1 family member with cancer	2 x 1940s, 4 x 1950s, 6 x 1960s, 3 x 1970s, 1 x 1980s, 2 x NR	2 Males, 16 females	90%
<b>Canada</b> Hammond et al. 2017 <sup>[35]</sup>	4 communities in British Columbia, Ontario, and Quebec	First Nations people	58 (31)	NR	Cancers of the breast, colon, kidney, skin, and non-Hodgkin lymphoma. Stage NR	NR	NCB	NR	75%
<b>New Zealand</b> Angelo and Wilson, 2014 <sup>[29]</sup>	South Island New Zealand; NFS	Māori	6 (6)	2	Cancer type NR; Hospice with prognosis of fewer than 3 months to live. Caregivers interviewed more than a year after death.	2x mother 2x wife 1x brother 1x husband	Mean: 51.8 y	2 Males, 4 females	70%
Frey et al. 2013 <sup>[37]</sup>	Hospice services in Auckland	Māori	52 (21)	6	Cancer type NR; 9 deceased, others were using or eligible for hospice services	Family member or bereaved family member, NFS	NCB	3 Males, 18 females	95%
<b>United States of America</b> Angela-Cole and Busch, 2011 <sup>[39]</sup>	Support groups associated with hospices, home health care agencies, and medical centers in Hawaii	Native Hawaiians	56 (12)	12	Breast, prostate, lung, pancreatic, uterine, bone, and brain cancers. Prognosis of 6 months or less live.	Family caregivers-82% of total sample were spouses; NFS.	Mean: 57.9 y	2 Males, 10 Female	85%
Hodge et al. 2016 <sup>[30]</sup> Hohl et al. 2016 <sup>[31]</sup>	Reservation sites and urban clinics in Arizona Tribal clinics in Oregon and Washington	Southwest American Indians American Indians and Alaska Natives	88 (61) 82 (11)	NR NR	Breast, colorectal, prostate, lung, and other cancers. 4x deceased patients	70% family members; 30% NFS NR	NR NR	35 Males, 53 females NCB	90% 95%

(continued)

**Table 2**  
(continued).

Author, year	Setting	Indigenous population	Entire sample size (caregiver sample size)	Sample of Indigenous caregivers	Survivors' cancer type and stage	Caregivers' relationship to indigenous survivor	Age of caregivers: mean/range	Sex of caregivers	Quality appraisal rating
Ka'opua et al., 2005 <sup>(42)</sup>	Hawaii; NFS	Native Hawaiians	26 (3)	3	7 × living survivors. Stage NR Survived 5+ y past prostate cancer diagnosis.	3 × spouse	Mean: 73.8 y (60–86)	3 Females	80%
Mokuau and Braun, 2007 <sup>(32)</sup>	Community sample in Hawaii	Native Hawaiians	25 (17)	NR	Breast cancer. Stage NR	6 × spouse 6 × mother or daughter 5 × other	Mean: 46 y (29 - 69)	3 Males, 14 females	75%

AMS = Aboriginal Medical Service, NCB = no caregiver breakdown, NFS = not further specified, NR = not reported.

*Mum, and then that would give Mum an indication that it's time for sleep and time for family to wind down and go to bed . . .* <sup>29, p.83</sup> (Māori)

Given the ongoing costs of treatment and associated factors, caregivers reported struggling to make financial ends meet throughout their journey with cancer.<sup>[30,35,39]</sup> Caregivers sometimes resorted to extreme measures to overcome these challenges, as described by one caregiver:

*“Spent my whole pay, \$1200 ‘cause it was an expensive flight out of the blue ... My sister flew in the same morning and her other half ... We all met at the hospital, we were there for 1 week without accommodation. We were in the waiting room sleeping with all our swags ‘cause we had no-one to organize accommodation at that time.”*<sup>39, p. 931</sup> (Aboriginal Australian).

Many caregivers provided survivors with a wide variety of practical support relating to transportation, cooking, personal care, household tasks, childcare duties, and medication management.<sup>[29,32,35,38]</sup> To cope with the stressors associated with this role, some caregivers looked to church congregations for respite care.<sup>[38]</sup>

Native Hawaiian caregivers provided support that was immersed in their cultural customs of “family caregiving,” with all family members contributing to the supportive role.<sup>[32,38]</sup>

*“Our elders are always taken care of—cancer or not. We do not need to designate a family caregiver, as everyone chips in to ensure care is provided.”*<sup>38, p.332</sup> (Native Hawaiian)

Although strongly expressed by Native Hawaiian caregivers, the important role of family caregivers was a strong theme throughout all caregivers' experiences.

**Communication challenges and responsibilities**

There was a lack of clear and effective communication between cancer survivors and their caregivers with health care providers. Some of these challenges were related to the ad hoc fashion in which caregivers received information as described above. Caregivers described being required to facilitate communication between the survivor and health professionals, and act as “cultural brokers,”<sup>[30]</sup> to explain cultural practices or beliefs (eg, illness-related beliefs, fears, and traditional medicines and ceremonies). Moreover, they acted as medical “decoders” by learning medical terminology to interpret medical results or explain treatment plans to the survivor.<sup>[30]</sup> Caregivers also played a major role in communicating the cancer diagnosis and treatment with family and community, and translating the meaning of cancer and prognosis, and initiating preparations for death and dying. This was often done in the survivor's Indigenous language.

*“ . . . in the end when he was told [by the provider] that he had terminal cancer, he asked people to explain it to him, so I told him in Apache what the doctors said and what it meant and the things they told him. . . .”*<sup>30, p. 224</sup> (American Indian)

Caregivers of some American Indian cancer survivors described cultural values of self-reliance, privacy, and personal space.<sup>[30]</sup> Their caregiving role involved adhering to these values

**Table 3**  
**Summary of meta-aggregation findings and implied caregiver needs**

Synthesized finding	Category	Summary of category data	Implied unmet needs of caregivers of Indigenous cancer survivors
Need for information about cancer and services	Knowledge and misconceptions about cancer	Some caregivers recognized that they did not know about cancer (signs, symptoms, course, prognosis, among others). Indigenous views and cultural beliefs about the origins of cancer should be considered in information provision. Caregivers (and survivors) found it difficult to have open discussions about cancer.	<ul style="list-style-type: none"> <li>Information on a range of cancer-related topics (eg., signs, symptoms, screening, course, prognosis)</li> <li>Knowledge of who/where to ask for information about cancer topics</li> <li>Culturally appropriate cancer resources</li> </ul>
Providing and receiving support	Silence about cancer Awareness of and access to services Desire for education about cancer	Caregivers (and survivors) found it difficult to have open discussions about cancer. Caregivers reported ad hoc information acquisition about services available to them, and were sometimes unsure of how they could engage with services. Caregivers expressed desires to learn more about cancer and treatment through a range of channels such as information brochures and counseling.	<ul style="list-style-type: none"> <li>Culturally appropriate resources to support talking with family and community about cancer</li> <li>Access to services (eg, respite, financial aid, transport, hospice services).</li> <li>Guidance on how services can be used (e.g., how long, when, where)</li> <li>Opportunities to learn about cancer and treatment through different channels (eg, written, diagrams, brochures, counseling, community information events)</li> </ul>
	Emotional and spiritual	Caregivers sought out emotional and spiritual support through support groups and prayer. Caregivers reported positive experiences with peer-support groups, and when health care providers demonstrated empathy and kindness.	<ul style="list-style-type: none"> <li>Access to emotional support</li> <li>Keeping strong in spirit or staying positive</li> <li>Having hospital staff show sensitivity to and respecting the caregiver's feelings and emotional needs</li> <li>Maintaining religious, spiritual, and/or cultural connections and practices</li> <li>Being connected with appropriate cancer support groups</li> <li>Support for provision of emotional support to survivor and others</li> <li>Access to financial support</li> </ul>
Financial	Caregivers struggled to meet the financial demands of cancer treatment and associated travel and often resorted to extreme measures (eg, sleeping in waiting rooms, spending entire pay cheque) to make ends meet.		<ul style="list-style-type: none"> <li>Access to respite services and other practical support services</li> <li>Access to accommodation while cancer survivor is receiving treatment</li> </ul>
Practical	Many caregivers stated that they required a wide variety of practical/tangible support, such as respite, transportation, cooking, grocery shopping, childcare duties, and monitoring of medications.		<ul style="list-style-type: none"> <li>Access to family and community support</li> </ul>
Cultural	Native Hawaiian caregivers reported the cultural customs of "family caregiving", in which all family members contribute to support and caring for the survivor. The importance of family caregiving was strongly expressed across the articles.		<ul style="list-style-type: none"> <li>Access to an Indigenous person who understands the caregiver's and survivor's culture to facilitate and/or interpret discussion with health professionals</li> <li>Access to information in the relevant Indigenous language</li> </ul>
Communication challenges and responsibilities	Decoder and cultural broker roles	Caregivers played a vital role in decoding medical information and explaining it to survivors, family, and community. Caregivers also played the role of "cultural broker," in which they communicated important cultural and community practices and beliefs to the treating team.	<ul style="list-style-type: none"> <li>Having cultural needs recognized and supported</li> <li>Access to cancer care that aligns with the needs of the carer and survivor</li> </ul>
Understanding of survivors' needs	Caregivers held valuable knowledge about the survivors' specific needs, which related to their culture, sex, nonverbal communication.		<ul style="list-style-type: none"> <li>Having appropriate resources (eg, a question prompt list) to support conversations with health professionals</li> </ul>
Communication with health professionals	Caregivers reported negative experiences when health care providers used technical medical jargon, whereas others reported positive experiences when health care providers communicated in an empathic and straight-forward manner, leading to a sense of reassurance		<ul style="list-style-type: none"> <li>Having a health professional who uses plain language without medical words</li> <li>Having a health professional who shows care and empathy toward you</li> <li>Having access to a patient navigator</li> </ul>

(continued)

**Table 3**  
**(continued).**

<b>Synthesized finding</b>	<b>Category</b>	<b>Summary of category data</b>	<b>Implied unmet needs of caregivers of Indigenous cancer survivors</b>
Balancing caregiver roles and emotions	Multiple roles	Caregivers took on additional roles, which often shifted throughout the caring journey to encompass various responsibilities. Roles between caregivers and survivors sometimes reversed (e.g., child caring for parent), and balancing multiple roles caused caregivers stress, but also brought families closer together.	<ul style="list-style-type: none"> <li>• Having counseling on how to manage life changes when caregiving</li> <li>• Having help to organise a busy schedule</li> <li>• Having help to manage caregiving roles</li> </ul>
Distress		The multifaceted role of caregiving was often associated with distress related to the managing the extensive responsibilities while watching the survivor suffer	<ul style="list-style-type: none"> <li>• Having someone to talk to about worries</li> </ul>
Culturally unsafe health systems and settings	Complex and alienating health system	Caregivers often reported feeling alienated and disoriented in the complex health care system, which made people feel physically and culturally unwelcome. Positive experiences included the assistance from a care coordinator, who provided support in navigating the hospital environment and competing medical demands.	<ul style="list-style-type: none"> <li>• Having access to a cancer care coordinator</li> <li>• Having co-ordination and continuity of cancer care</li> <li>• Directions to get to and around the hospital</li> </ul>
	Family-focussed care	A need for family-focussed care was expressed, where health care providers included the entire family in the survivor's treatment and care. Caregivers reported positive experiences when healthcare providers were family rather than patient-focussed	<ul style="list-style-type: none"> <li>• Access to a health professional who includes the whole family in treatment and care decisions</li> <li>• Access to spaces where family can gather in the hospital</li> <li>• Ensuring family members can be present when talking to or seeing health professional</li> </ul>
	Mistrust and experience of racism	Caregivers reported mistrust of health care institutions due to their experiences of marginalization and racism.	<ul style="list-style-type: none"> <li>• Being respected as a person</li> <li>• Having a cancer care medical team who respects the carer's and survivor's culture</li> <li>• Access to culturally safe care</li> </ul>

and explaining them to medical staff so they could understand why the survivors were unwilling to discuss their illness with staff or family:

*“ . . . cancer and diabetes are some of the things that they don’t talk about . . . it is too personal to talk about it.”*<sup>30</sup>, p. 226 (American Indian)

An important caregiver role included communicating in culturally sensitive ways, such as recognizing the appropriate contexts in which to communicate directly and honestly, reading nonverbal cues, and giving help without being asked.

*“The Elders might not say anything to you but you know what they’re thinking by their gestures, by their body language, by the way they move their eyes and stuff. . . . we have to learn to look beyond . . . what the patient is saying, you have to look at what they’re not saying.”*<sup>35</sup>, p. 195 (First Nations, British Columbia, Ontario, and Quebec)

Caregivers described some positive communication experiences with health professionals which were characterized by the use of plain language, providing written materials, encouraging the cancer survivor and caregivers to contact them for further information if needed, and a general sense of empathy and understanding.

*“The doctors really made a big difference. They worked to break it down into terms that we could understand . . . it just felt he really cared . . . It just made us feel better . . . it just felt really good that he was on our side.”*<sup>31</sup>, p. 2440 (American Indian and Alaska Native).

Conversely, health professionals’ use of medical jargon made communication more difficult,<sup>40,41</sup> indicating a need for simple and accessible explanations:

*“ . . . we would ask her, ‘Well, what’s wrong? You know, what did the doctor say?’ ‘Oh, I don’t know; I can’t remember’, yeah, because they talk in technical terms, you know, medical terms . . . ”*<sup>41</sup>, p. 4 (Aboriginal Australian)

As described in the section regarding caregivers’ need for information about cancer, health professionals’ communication needed to be sensitive to Indigenous peoples’ values and cultural beliefs about cancer.

### **Balancing caregiver roles and emotions**

Caregiving necessitated changes and additions to their usual roles and responsibilities, which sometimes led to feelings of guilt and sadness.<sup>30,32</sup> Sometimes traditional family roles switched, such as a daughter caring for her mother, which could trigger sadness and confusion.<sup>32</sup> Caregivers described forgoing self-care practices to accommodate pressing survivor needs. Caregivers’ responsibilities included financier, driver, support person, interpreter, cook, housekeeper, carer for other family members and parent.<sup>30,42</sup> Moreover, caregivers assumed roles related to: providing emotional support, managing treatments and medications, coordinating care, minimizing conflict, and accompanying survivors to medical appointments. Caregivers took on the difficult role of “gatekeeper” by restricting visitors to ensure the cancer survivor could rest.<sup>29</sup>

The multifaceted caregiving role was often associated with feeling overwhelmed, uncertain, distressed, fatigued, depressed and anxious, which often placed strain on the survivor–caregiver relationship.<sup>30,38,42</sup> Tension between family members sometimes emerged as they came to terms with the cancer diagnosis and caregiving roles.<sup>29</sup> Caregivers were faced with the prospect of caring for loved ones while also witnessing the deterioration of their health.

*“I know she does not want any preferential treatment . . . she wants to be treated normal, and yet sometimes I see her face and I know she is sick, and so it is really hard. How do you deal with that? So I find myself in a real situation.”*<sup>31</sup>, p. 225 (American Indian)

Although shifts in family dynamics often engendered adverse emotions, caregivers also emphasized the positive aspects of the role, such as becoming closer and spending quality time with family.<sup>30,32</sup>

*“ . . . I know it caused a lot of pressure on the family, short tempers, and it also brought the family a little closer together. . . . after the sickness, it brought us together and we were always around her [the cancer patient] as much as possible, rotating, helping her with household chores . . . ”*<sup>30</sup>, p. 225 (American Indian)

### **Culturally unsafe health systems and settings**

Culturally unsafe health care is defined as health care practice that undermines an individual’s cultural identity and well-being.<sup>43</sup> This emerged as an important factor in caregivers’ experiences. Caregivers described feeling alienated, disoriented and disempowered in a complex health care setting.<sup>39</sup> The physical appearance, size, and layouts of large scale, tertiary treatment facilities were overwhelming and confusing, particularly for caregivers from rural and remote areas.<sup>41</sup> Hospital settings disrupted Aboriginal Australians’ close bonds to Country<sup>41</sup> (a multidimensional concept encompassing more than the physical elements of earth, sky, and sea, and strongly interconnected with spirituality, identity, and culture.<sup>44</sup>)

Conflicting rules and regulations and lack of communication between cancer care providers and primary care providers caused frustration for survivors and caregivers.<sup>31</sup> However, care coordinators helped caregivers navigate the health care system and facilitated communication:

*“Our head’s not even screwed on, we’re not thinking straight. We’d rather deal with one person, that’s what [care coordinator] does. We deal with her and she tells anyone to sort anything out for us and then it gets sorted..”*<sup>39</sup>, p. 932 (Aboriginal Australian)

Seeing other Indigenous people as members of the health care team made survivors and caregivers feel welcomed.<sup>41</sup>

Caregivers reported a preference for family-focussed care, often involving many people rotating through various tasks.<sup>29</sup> Palliative care sometimes took place within family homes.<sup>29</sup> Caregivers reported negative experiences when health care systems did not accommodate Indigenous cancer survivors’ and caregivers’ preferences to include families in treatment and care discussions.<sup>32,37</sup> Some families felt intimidated by health professionals providing patient-focussed rather than family-

focussed care and this prevented them from asking for further information.<sup>[32]</sup> Positive experiences were reported when caregivers and family were included and accommodated in the provision of care for the survivor:

*“They supported us as a family in every way. For if we wanted to stay over, we could stay over. There was no restriction. . . . She [the patient] was never left alone.”*<sup>41, p. 4</sup> (Aboriginal Australian)

Indigenous peoples’ collective experiences of racism and lack of respectful care led to caregivers reporting mistrust of Western biomedically focused health care.<sup>[35,36,39]</sup> These experiences directly impacted caregivers’ and survivors’ decisions to engage with cancer treatment.

Caregivers reported health professionals’ racism toward Indigenous cancer survivors.

*“Every time [my partner] goes into the hospital, he is treated like a piece of dirt. And then he ends up discharging himself because he doesn’t get proper treatment.”*<sup>36, p. 376</sup> (Aboriginal Australian)

### Implied caregiver needs

A list of unmet needs of caregivers of Indigenous cancer survivors extrapolated from the analysis of caregivers’ experiences is provided in Table 3.

## Discussion

The aim of this review was to explore and describe the experiences of caregivers of Indigenous cancer survivors in Australia, Canada, New Zealand, and United States reported in qualitative research. Through a meta-aggregation approach, 5 major areas emerged broadly relating to information, support, communication, balancing roles and emotions, and culturally unsafe health care systems and settings.

The findings complement and extend the findings of a systematic review of quantitative research relating to Indigenous caregiver functioning, which reported that Indigenous caregivers experienced poorer mental health and quality of life, and greater caregiver burden than non-Indigenous caregivers.<sup>[8]</sup> Furthermore, many of the experiences of caregivers of Indigenous cancer survivors in this review were similar to those of partners and caregivers of non-Indigenous cancer survivors reported in a review of unmet needs conducted by Lambert et al, 2012.<sup>[12]</sup> Our review identified additional caregiver experiences that are specific to, and more likely to compound, the challenges faced by caregivers of Indigenous cancer survivors, compared to caregivers of non-Indigenous cancer survivors. These were: a preference for family-focussed care, a need for culturally safe cancer care, and the role of “cultural brokers” on behalf of the cancer survivor, as explored below.

An important finding was caregivers’ preferences for family-focussed care, as opposed to a single individual family caregiver and patient-focussed care. This was evidenced in the inclusion of multiple family members as caregivers, a preference for in-home palliative care and for the inclusion of family in treatment and care decisions, and the cultural expectation of care provision by family.<sup>[29,32,38]</sup> In Indigenous cultures, family involvement in care is common practice.<sup>[45,46]</sup> Although other studies and populations report family caregiving,<sup>[13]</sup> the centrality of family to many Indigenous populations’ notions of health and wellbeing<sup>[47,48]</sup> is

consistent with preferences for family-focussed care and involvement in decision-making and may buffer some of the stress of the transition from family member to caregiver.

Our review supports the existing literature with regards to Indigenous people experiencing a lack of culturally appropriate cancer care,<sup>[49–51]</sup> and the impact this has on their ability to access support services such as transport and accommodation.<sup>[46,52,53]</sup> Experiences of racism leading to institutional mistrust<sup>[51,54]</sup> have also been described in the literature as barriers to Indigenous cancer survivors receiving equitable access to and use of health services.<sup>[52]</sup> In this review, caregivers of Indigenous cancer survivors reported similar issues and experiences. These findings highlight the need to create culturally safe health care environments that are welcoming, comprehensive, holistic, and inclusive of key family members and/or caregivers.

Caregivers were required to act as “cultural brokers” or “decoders”<sup>[30]</sup> between the health care team, family, and cancer survivor that included responsibilities for managing multidirectional and complex communication that was overlaid by cultural responsibilities. This highlights the communication challenges in cancer care faced by survivors and caregivers reported in previous research.<sup>[46,49–51]</sup>

Aboriginal Australians reported feeling disconnected from Country in hospital settings. Indigenous people worldwide have strong bonds to traditional lands, often linked to well-being and expression of spirituality through cultural customs and practice.<sup>[47,55,56]</sup> Requiring survivors to attend medical appointments far from home and Country disrupts connection to Country and indicates survivors and caregivers should be supported to feel connected to their traditional lands, cultural customs, and practices during treatment.

Finally, it is important to note that many of the synthesized findings and categories overlap considerably, compounding their cumulative effects on caregivers. For example, health professionals’ inappropriate communication techniques and culturally inappropriate cancer information and education all contribute to culturally unsafe health systems and settings that are not designed with Indigenous peoples and cultural diversity in mind. Together, these factors combined to create barriers for caregivers in navigating health care systems and supporting survivors to engage in cancer care.

### Clinical implications

The synthesis of caregivers’ experiences demonstrates that many caregiver needs remain unmet in clinical care. As caregivers occupy the dual roles of both co-workers on the survivor’s medical team and co-clients, their needs as co-clients often go unnoticed.<sup>[5,57]</sup> Service providers focus on the patient and often have little time to undertake comprehensive screening for family caregivers’ problems. A family caregiver’s assessment is often informal and undocumented, making family caregivers’ support needs less “visible.” Family caregivers are also often reluctant to express their own needs and are unlikely to feel their needs are legitimate.<sup>[58]</sup> Therefore, a systematic tool for identifying and addressing caregivers’ unmet needs would improve the quality of care for caregivers of Indigenous cancer survivors. Such a tool does not currently exist.

A supportive care needs tool developed for Indigenous Australian cancer survivors<sup>[59]</sup> indicated that 71% reported at least 1 unmet need, with the most frequently reported unmet needs in the financial, psychological, and physical domains. This suggests that their caregivers may have similar unmet needs. In

Table 3, we provide potential unmet needs of caregivers of Indigenous cancer survivors extrapolated from our analysis of caregivers' experiences. It is important to note that this list is not exhaustive as the domains are restricted to the topics covered in published articles, most of which did not focus on caregiver needs exclusively. The list and findings of the review may inform the development of a tool to assess unmet needs specific to caregivers.

**Limitations and future directions.** We recognize the diversity of Indigenous peoples from the countries included in this review however, despite this diversity, many Indigenous people across the world, continue to face similar substantial economic, health, and social disadvantages as a result of an enduring legacy of colonization. We therefore recognize that pooling data across these countries may disguise the wide diversity of language, geography, health systems, and cultural practices of Indigenous groups both within and between these countries. The generalizability of the findings may be limited to English-speaking Indigenous populations from high income countries. Furthermore, few articles were obtained from Canada and New Zealand, skewing the findings toward caregivers from Australia and United States.

The review was conducted by both Aboriginal Australian researchers and other Australian researchers, who collectively have expertise in the areas of cancer care, Indigenous Australian health research, and caregivers. A limitation of this approach was that no authors represented the Indigenous populations from New Zealand, Canada, and United States.

Only 2 articles<sup>[29,30]</sup> focused exclusively on caregivers' perspectives, with most articles including caregivers' voices as a way to augment the stories of Indigenous cancer survivors. Future research should explore the experiences of caregivers of Indigenous cancer survivors in greater depth, ensuring that their voices are heard so that their needs can be identified and met. For example, growing research indicates that there are positive and beneficial experiences of caregiving, an idea which merits further investigation among caregivers of Indigenous cancer survivors.

The cancer stage of survivors was rarely reported, so we cannot make comment on how caregivers' needs or experiences may change according to the survivor's cancer stage or over time. This is an area to be explored in future research.

## Conclusions

The findings of this review indicate that caregivers of Indigenous cancer survivors have unique experiences, which suggest unmet needs in clinical care. A systematic approach to identifying their unmet needs would be valuable in clinical practice. Ensuring that caregivers' needs are supported not only improves their well-being but may also improve the wellbeing of the people they care for and contribute to reducing disparities in outcomes for Indigenous cancer survivors.

## Conflicts of interest statement

The authors declare no conflicts of interest.

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