Supplemental Digital Content, Table 2. Meta-Aggregation Table

| **Synthesised Finding** | **Category** | **Extract** | **First Author (Year), Country** | **Page** | **Participant information (if provided)** |
| --- | --- | --- | --- | --- | --- |
| **Need for information about cancer and services** | | | | |  |
|  | **Knowledge and misconceptions about cancer** | | | |  |
|  |  | Regardless of their initial level of understanding of cancer care, the survivors and caregivers who were satisfied with care said their care providers mitigated this multi-level burden by offering informational support and building health literacy. Providers delivered informational support through multiple means, including conversations during appointments, written materials to read at home, and open invitations to contact the provider should questions arise. | Hohl (2016)1, United States of America | 2440 |  |
|  |  | Blaming others or a particular life experience as a cause of sickness is widespread within Aboriginal communities where spirituality exerts a powerful influence upon the notion of wellbeing. Such attribution of cancer to spiritual causes can lead to fatalism, acceptance of the disease without question and not seeking help for it – “Aboriginal people have this notion of being sung... it's basically a bad magic put on somebody.” As a consequence of such beliefs, people may feel ashamed about their "wrong-doing" and hide their symptoms from others, delaying diagnosis or not pursuing treatment. As stated by one family member: “...it was almost like you deserved it or there was definitely this sense of shame. It was whispered. If someone died of a heart attack you would say that, but... all this cancer stuff was a whispered sort of stuff.” | Shahid (2009)2, Australia | 132 |  |
| Close family members were often unsure about what was happening to relatives and felt they could have helped more had they been better informed or more knowledgeable. Comments such as ‘we didn't know what was happening” and “We didn't know that she got cancer until she died” were common. These comments reflect communication problems for Aboriginal people within health facilities, and ignorance about cancer symptoms such as weight loss, anorexia and bleeding. “I didn't relate dad's condition to cancer. I found out later when I read up about it ...it was... almost ten years after I lost my dad.” | Shahid (2009)2, Australia | 132 |  |
| Community understandings of cancer were described by each group of participants as low and as imbued with myths or misunderstandings. Equating a cancer diagnosis to a ‘death sentence’ was a strong theme in these data. Carina (a carer) described cancer as “a big silent word...you mention cancer and God, every-body just caves in.” | Treloar (2013)3, Australia | 659 |  |
| Patient and carer participants described limited cancer knowledge, experience or expectation prior to the diagnosis that affected them. Nola (a carer) commented that she “didn’t really think that cancer would touch my life”. Tom (a carer) revealed that he did not know what an oncologist was until his daughter was given an appointment to see one. | Treloar (2013)3, Australia | 659 |  |
| **Silence about cancer** | | | |  |
|  | Beyond this legacy of grief, participants provided a second historical source to cycles of silence, related to colonization of their communities. For instance, residential schools had a major impact on how survivors and caregivers communicated with each other. Chantal, a bereaved caregiver to her mother, talked about the legacy of the schools and how they influenced her family's interactions when her mother experienced throat cancer: “I don't talk to my sisters anymore because we come from an Ojibway family that was really ruined by the residential schools. The dynamic that was taught at the schools was, ‘Keep secrets, don't tell the truth,’ because the truth might hurt someone or you might hurt yourself and get into trouble… communication would have solved a lot of problems but the dynamic in residential schools was, ‘Don't communicate, keep everything secret,’ and then the families perpetuate that rotten dynamic and that's exactly what we got to and I've just had to leave my family behind.” | Hammond (2017)4, Canada | 193, 194 | Bereaved female caregiver of her Ojibway Mother with cancer |
|  | The cultural restriction for not discussing illness openly was an important barrier to patient communication. Overcoming this delicate situation became an important role for the caregivers for the management of cancer pain and other symptoms. Caregivers tell of running “into people I am talking with and they ask me if I know anything about certain diseases, we talk about what we both know.” Talking about cancer was taboo thus fearful as saying the word “cancer” may bring forth the disease, because the fear ... of the word itself was something the community would not acknowledge.” | Hodge (2016)5, United States of America | 226 |  |
| In addition, all participant groups noted the large number of other health conditions that were of priority for Aboriginal communities, which further silenced discussions of cancer. | Treloar (2013)3, Australia | 659 |  |
| **Awareness of and access to services** | | | |  |
|  | Contrary to the reality of the situation of free services for all (Hospice New Zealand 2012) there was a perception that hospice services are only available for persons with an inability to pay. They equated the service with being on unemployment benefit, which was viewed with a sense of shame. | Frey (2013)6, New Zealand | 524 |  |
| Family/whānau of former patients also did not understand how they could utilise the hospice services. For example they were unaware that they could use hospice services for a couple of days respite rather than a week at a time. | Frey (2013)6, New Zealand | 522 |  |
| Patients and families often reported a lack of familiarity with the role of hospice services or the services available. There was a lack of awareness that ‘care and support’ could be found in a range of services which were easily accessible and ‘user friendly’. For example, they were unaware that they could use it for a couple of days respite rather than a week at a time. | Frey (2013)6, New Zealand | 522 |  |
| “…In addition, caregivers facilitated introduction and discussion of services often unfamiliar to members of the community. There is another thing ... hospice ... there is a lot of people [that have cancer] that don’t know about that ... and they deal a lot with those patients. A lot of people are not informed of the things that are available to them ... the different types of services.” | Hodge (2016)5, United States of America | 225 |  |
| Aboriginal and non-Aboriginal patient and carer participants described confusion about financial assistance programs resulting in the lack of uptake of support for transport, temporary accommodation and housing expenses. Patient and carer participants described a process of ad hoc informal information acquisition provided by family and peers. | Treloar (2014)7, Australia | 377 |  |
|  | **Desire for education about cancer** | | | | |
|  |  | First, most participants (72%) recommended family counseling in the medical office with information on the stages of cancer and options or treatment, ways to navigate the health care system, and the identification of resources to support both the survivor (e.g., Meals on Wheels) and the caregivers (e.g., respite care). Second, they (68%) emphasized the importance of medical and other literature (e.g., brochures, pamphlets) that the family can take home and share with other members. Third, participants (56%) identified outreach and home-visiting services to educate the family and teach them skills (e.g., household management) on how to support their loved one. | Mokuau (2007)8, United States of America | 194 |  |
|  |  | The majority of participants expressed a need for increased information to be provided to Aboriginal communities about this ‘bloody disease’. Specifically, information was required that facilitated community members’ awareness of cancer as well as its meanings, signs and symptoms, so that they were able to engage in testing and prepare for diagnosis and treatment. | Treloar (2013)3, Australia | 660 |  |
|  |  | Participants drew comparisons between education programmes on a range of other health issues that they knew of or had been involved in (as participant tor educator), but typically stated that they knew of few, or no, such programmes for cancer. | Treloar (2013)3, Australia | 660 |  |
|  |  | There was an expressed need for cancer education programmes at a number of levels–for community members and for health workers: “There’s no information session at the ground roots, on the reserves and that to speak to people...I belong to the Aboriginal Women’s [group]...we had all these information sessions, but I don’t think we had one on cancer. We done a lot of women’s problems, but we didn’t touch on cancer and I guess it didn’t even come to mind anyway, what I can remember we didn’t, you know, it wasn’t talked about.” | Treloar (2013)3, Australia | 660 | Female carer |
| **Providing and receiving support** | | | | | |
|  | **Emotional and spiritual** | | | | |
|  |  | All informants except Informant 4 (Chinese, male) talked about spirituality.  For Informant 1, spirituality took the form of religious rituals that the entire Māori family participated in nightly: “I would give Mum her medicine, and about 8 p. m. we had a prayer time. The whole family would go in [Mum’s room] and pray and talk to God and sing. Then all the children would kiss 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. Lights would be dimmed, and Mum would have a wipe-down and medicine and things.”  Informant 2 also said his family prayed in the morning and evening when they were together. … The Māori male, the Tongan female and the Tongan male (Informant 6) prayed with their family members and religious leaders. They also sang and attended religious meetings with their ill family members when possible | Angelo (2014)9, New Zealand | 83 | Informant 1: Māori, female  Informant 2: Māori, male |
|  |  | All of the participants reported that the caregiver support groups they were attending were helpful. An essential component was the ability to call other caregivers from an established hot-line of caregivers as a way of dealing with immediate feelings of being overwhelmed. | Anngela-Cole (2011)10, United States of America | 328, 329 |  |
|  |  | All groups indicated that attending the support groups helped with coping with the sadness they felt while caregiving. They said they felt ‘‘understood’’ by others who were going through it, as indicated with the following quote stated by a Native Hawaiian participant: ‘‘We all suffering da same.’’ They also said that prayer helped them, particularly among the Hawaiian group. | Anngela-Cole (2011)10, United States of America | 330 |  |
|  |  | The Native Hawaiians tended to rely on prayer and expressed a belief that God will provide them with what they need to cope. The following quote from a Native Hawaiian participant exemplifies the above sentiment: ‘‘Our situation is in God’s hands, and he will keep us whole’’; meaning as a whole family that includes ancestors. | Anngela-Cole (2011)10 , United States of America | 330 |  |
|  |  | [Caregivers looked for] emotional and spiritual counseling for distress… | Hammond (2017)4, Canada | 194 |  |
| There is space for truth‐telling as well, but it depends upon the context. It must be the right person speaking and the right time to talk, as Chantal explained: “Sometimes you just need to get the message from the right person too. An Elder told me, “Pull yourself together. Your mother doesn't want to see you being a mess like this.” And then, within two days I'd stopped my crying, I'd stood up straight, I took a shower. I hadn't showered in five days. And then I just got on with the business of helping my mom get through treatment.” | Hammond (2017)4, Canada | 195 | Bereaved female caregiver of her Ojibway Mother with cancer |
| Summarizing his family member’s cancer care experience, this caregiver reported, “The family support, the doctors, and information combined just made things more reassuring that what we were doing was right, caught it in time, and everything’s going to be okay.” | Hohl (2016)1, United States of America | 2441 |  |
| The survivors and caregivers said providers showed support by demonstrating kindness and care and by acknowledging their struggle. | Hohl (2016)1, United States of America | 2441 |  |
| All 25 participants reported the rendering and receipt of emotional support. Emotional comfort was reflected in multiple expressions of reassurance and love. For example, 1 husband said it became more important to reassure his wife of his love because of her insecurity of “not being quite as good after her mastectomy.” | Mokuau (2007)8, United States of America | 193 |  |
| **Financial** | | | | |
|  | [Caregivers looked for]... financial aid for expensive medical travels. | Hammond (2017)4, Canada | 194 |  |
|  | Another topic often shared with providers was the barrier to cancer care faced by American Indian patients. Caregivers identified such barriers as lack of transportation, lack of knowledge regarding resource availability, and the expenses associated with hospitalization and death and dying. One caregiver explained, “... most of the household money goes to her travel ... and we have issues at home ... pay for bills ... propane, electricity ... some of us have food stamps so we have to pitch in to get food and stuff ... because all that money goes to ... she gets ... goes to her transportation [to the hospital]. We don’t have money for household stuff. A lot of us don’t work because there are no jobs around here.”  “When she was in the hospital, I know it was a financial burden because she was in Phoenix and traveling from here to Phoenix was expensive, especially on gas. And not having family in the Phoenix area was another problem because we had to pull money together to get a room, gas money, and food, but that was toward the end when she was about to go.” | Hodge (2016)5, United States of America | 226 |  |
|  | Organizing travel, accommodation and supportive care needs for patients and their families was a key component of care coordination. Travel was often an expensive burden for patients and their families, added to the cost of having to take time off work for treatment. When care coordination support was absent, some families described resorting to inappropriate or uncomfortable options, such as taking long bus trips while in severe pain or having nowhere to stay: “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 organise accommodation at that time.” | Reilly (2018)11, Australia | 931 | Aboriginal carer 4 |
| **Practical** | | | | |
|  | All six informants were concerned about preparing nutritious meals for their ill family members… The Māori and Tongan male and female informants also prepared foods familiar to their families. For example, the sister of Informant 1 and the niece of Informant 2 each made stews. “When I got home, they were already there and having a big feed”, Informant 2 said. “I had cooked stew in a pot, and it takes about four hours to cook— slow cooking.” | Angelo (2014)9, New Zealand | 83, 84 | Informant 1: Māori, female  Informant 2: Māori, male |
|  | Only Informant 1 specifically described assisting her mother to the toilet:  She started off in the room closet to the toilet. It was a smaller. So then we changed rooms. It was only a few meters away, but for her it may have been ten miles. As she got weaker she needed a commode, and my job, or whoever was there [it was] job, was to put her on the commode. And then I would take it out and pretty much clean it straight away. And we had a way of disinfecting it and what not. So that was travelling down to the second bathroom downstairs. That was good because I lost a bit of weight doing that. | Angelo (2014)9, New Zealand | 86 | Informant 1: Māori, female |
|  | There was a resounding desire for respite as a means of reducing the difficult conditions of caregiving. | Anngela-Cole (2011)10, United States of America | 330 |  |
|  | They also relied on their church congregations for all types of support, including social and monetary support, and respite care." | Anngela-Cole (2011)10, United States of America | 330 |  |
|  | [Caregivers looked for] …caregiver support for exhausted families. | Hammond (2017)4, Canada | 194 |  |
| Survivors and caregivers alike looked to institutions for respite. | Hammond (2017)4, Canada | 194 |  |
| Nearly 90% of participants indicated that tangible support was provided, such as *kokua* (assistance) with medical and personal care, household maintenance, and childcare. Common examples included transportation to appointments, monitoring medications, grocery shopping, cooking, and taking children on outings to provide some respite for the women. | Mokuau (2007)8, United States of America | 193 |  |
| **Cultural** | | | | |
|  | "...In contrast, the Native Hawaiian participants stated that ‘‘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.’’ | Anngela-Cole (2011)10, United States of America | 331 |  |
|  | The Native Hawaiian group did not appear to recognize stress at all. They stated beliefs that providing care to family members is common place, and just ‘‘something you do if you are Hawaiian.’’ | Anngela-Cole (2011)10, United States of America | 328 |  |
|  | The Native Hawaiians were unique in their perceptions of caregiving responsibility based on their traditional custom of intergenerational living arrangements. In the Hawaiian culture, there is always someone who is ill or frail due to age, and therefore ‘‘there is no question that someone is always available to provide the care.’’ Children are taught from a young age that they are responsible for helping the family system to take care of anyone who needs assistance." | Anngela-Cole (2011)10, United States of America | 331 |  |
|  | The discussion consistently emphasized the cultural expectation that *kokua* (assistance) would be forthcoming from every family member. | Mokuau (2007)8, United States of America | 193 |  |
| **Communication challenges and responsibilities** | | | | | |
|  | **Decoder and cultural broker roles** | | | | |
|  |  | Communicating with the patient often required “decoding” or making sense of the medical terms and describing cancer in both etiology and trajectory terms of the disease. Focus group participants reported that caregivers become well versed in basic medical terminology – specifically oncology – out of necessity, because patients depended on them to interpret medical findings, as well as to support and encourage the treatment protocol. The caregiver typically spoke the native language of the patient, or would find someone to interpret for them. Several caregivers commented about translating during medical visits. Items translated included information of impending death, information on treatment such as the schedule for chemotherapy, or the name of the medication prescribed by the physician, and the treatment regimen. One caregiver shared a situation where the patient wanted to have provider’s information explained to him, “…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. Later on he just lowered his head and said ‘Adalezy, there is no hope’.” | Hodge (2016)5, United States of America | 224 |  |
|  |  | The caregivers who reported that they were most successful in their roles acted as “cultural brokers” – they were knowledgeable of the culture-bound illness beliefs, fears, and traditional treatments and ceremonies. Understanding the cultural constructs of illness, having a strong understanding of the illness beliefs, particularly the onset and trajectory of cancer and cancer pain management are important attributes of the caregiver. | Hodge (2016)5, United States of America | 226 |  |
|  |  | The cultural value of self-reliance and the importance of respect, privacy, and personal space (comfort with being touched or handled by strangers) among tribal groups are important and the caregiver must abide by those values and to translate the cultural values to the medical care personnel. One caregiver shared, “cancer and diabetes are some of the things that they don’t talk about ... it is too personal to talk about it.” A common phrase among the caregivers was “we don’t talk about it” to spare additional hardship on family members because “we don’t bring our burdens home.” These beliefs and communication restrictions were shared with the medical providers so they could understand why patients do not talk about their illness and why they do not often share it with their family members,“… my dad was like that too, he was kind of traditional. I know a lot of the older people are really traditional …My dad, he passed on already so you don’t talk about it…They said once they are gone, they are gone … they don’t talk about them.”  “I know my uncle admitted he knew there was something wrong. He was smoking. There were certain things that were happening. I think they know, but they don’t talk about it. I think they know but keep to themselves.” | Hodge (2016)5, United States of America | 226 |  |
|  |  | Sharing the diagnosis with the family and translating the meaning of cancer, expected trajectory of the disease, and preparation for death and dying are major roles of the caregiver. A caregiver explained, “My doctor told me ... that I have to share with family members, like cousins or anyone who was close ... notifying the family that she might die that week, and that the family be prepared, and to know that she will be gone.” | Hodge (2016)5, United States of America | 224, 225 |  |
|  | **Understanding survivors' needs** | | | | |
|  | Participants suggested that communication is often indirect and nonverbal when someone in the community is ill. It was seen as important not to treat silence as a barrier in itself but to understand its various roots and effects. For example, the challenge of being able to speak was sometimes reframed as a call for caregivers to learn how to hear and understand what is expressed in silence. Chantal said that good caregivers know how to help without needing to be 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. That might be a hard language for anyone to learn but we have to learn to look beyond what the person says, what the patient is saying, you have to look at what they're not saying.” | Hammond (2017)4, Canada | 195 | Bereaved female caregiver of her Ojibway Mother with cancer |
| Caregivers are also knowledgeable of the specific needs of gender or age groups. A caregiver commented, “I think they need time to grieve ... men hide problems, my father was very sick, he did not tell us what is wrong till the end…” | Hodge (2016)5, United States of America | 225 |  |
| **Communication with health professionals** | | | | |
|  | Even caregivers observed that providers further helped patients understand their treatment by explaining processes in a straight-forward language, as illustrated by this caregiver, who said: “The doctors really made a big difference. They worked to break it down into terms that we could understand, and it was really reassuring as far as how the outcome would be, and it just felt he really cared about his patients. It just made us feel better, and he was very confident in how he talked to us, and it just felt really good that he was on our side.” | Hohl (2016)1, United States of America | 2440 |  |
| The survivors and caregivers further widely reported that care providers’ empathic communication practices contributed to satisfaction. | Hohl (2016)1, United States of America | 2440 |  |
|  |  | “I know what you mean by information, doctors in the oncology unit they see it all the time but we don’t…He [husband] says ‘sis I don’t know what’s going on’ … and I got doctors to sit down with me, had the liaison officers in on our meetings with the doctors. And I said ‘explain it to us in English now’. Plain language and draw a diagram so you see where and show us what happened.” | Meiklejohn (2019)12, Australia | 4 | Aboriginal Female carer |
|  |  | Participants commented that they felt their own and their family members’ concerns were not listened to or acknowledged by staff, with some reporting an unwillingness of medical staff to be forthcoming about the severity and prognosis of their illness: “They would upset her and she would ring us and say, ‘Can you come in? The doctor has just been in’. Then 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. Patients can’t understand medical terms.” | Thompson (2011)13, Australia | 4 | Urban, female family member |
| **Balancing caregiver roles and emotions** | | | | | |
|  | **Multiple roles** | | | | |
|  |  | All informants mentioned that at times, they played the role of gatekeeper by restricting the number of visitors when the ill family member was feeling unwell, was too weak to socialize or was sleeping. At these times, visitors were seen as an intrusion. Informants found the gatekeeping job difficult but necessary.  Associated with visitor gatekeeping were four sub-occupations. The first was ensuring the family member was clean and presentable. The second was making sure the house tidy before visitors arrived. Then a pot of tea needed to be brewed, and homemade or store-bought muffins needed to be offered. Finally, there was the clean-up after the visitors left. Informant 1 (Māori, female) put it this way: “I would give her a wipe-down at night or before someone visited.” | Angelo (2014)9, New Zealand | 85, 85 | Informant 1: Māori, female  Informant 2: Māori, male |
|  |  | As caregiver family members (or individuals close to the family) took on the responsibility of staying with the patient at all times, they assumed the role of the mother, interpreter, driver, cook, housekeeper, and health care aide. Most participants reported living with the cancer patient and would provide transportation to medical appointments particularly “if they don’t know anyone going [they will] volunteer to go with them.” A caregiver shared, “... sometimes family have to stay overnight, sometimes you have the van take you to IHS [Indian Health Service clinic or hospital], but they don’t stay around to take you back, so you have to stay overnight and make arrangements.” | Hodge (2016)5, United States of America | 225 |  |
|  |  | The cancer diagnosis and treatment took quite a toll on family roles and dynamics, changing relationships and expectations, “For my aunt, I know it disrupted her life because she was unable to do anything for herself, she couldn’t be a mother ... I know it caused a lot of pressure on the family, short tempers, and it also brought the family a little closer together. At the time I wasn’t really actively involved with that side of the family, but then after the sickness, it brought us together and we were always around her – being around her as much as possible, rotating, helping her with household chores ...” | Hodge (2016)5, United States of America | 225 |  |
|  |  | Almost all participants identified role changes and the shift in their responsibilities (*kuleana*). *Kuleana* in Hawaiian families refers to the assumption of specific roles and responsibilities based on factors such as interest, rights, and accountability. For 5 family participants (30%), the role changes included “additional” responsibilities. For example, 1 daughter stated “My mother was unable to care for herself, but was unwilling to live with me, so I had to run my parents’ household, as well as my own.” All survivors experienced guilt in observing their family members taking on additional roles. | Mokuau (2007)8, United States of America | 194 |  |
| Although the role changes typically added familial responsibilities, engendered stress, and contributed to emotions such as guilt and sadness, they also served to strengthen the family. Several noted that the “family got closer” as they pulled together to support their loved one and that the priorities became clearer. For example, 1 husband said “I became more aware of her, and wanted to spend more time with her and the kids … my job became less important.” | Mokuau (2007)8, United States of America | 194 |  |
| Five (30%) of the family members, told of role changes that “reversed” the responsibilities of the survivor and family member, which prompted emotions such as sadness and confusion. A daughter who was the primary support for her mother with breast cancer said “I became mother, and she became the child. She was very dependent on me.” | Mokuau (2007)8, United States of America | 194 |  |
| Women were actively involved in activities focused on keeping their husbands healthy and had encouraged initial screening for prostate cancer. Once their husbands were diagnosed with prostate cancer, approximately 85 percent (*n* = 22) of the women helped their husbands navigate the medical system. They reported accompanying their husbands to medical appointments and treatments, discussing treatment options with their husband and other family members, and providing or facilitating social support. “The doctor said that my husband had two treatment choices. We came home and had a family *pule* [prayer] about what to do. We talked as a family and then made the decision.” | Ka’opua (2005)14, United States of America | 149, 150 | Native Hawaiian caregiver for her husband |
| **Distress** | | | | |
|  | As connected as the family [of Informant 1] was, a brother lived in another town who was less involved in the care. Family members did not expect him to move in as they had, but they expected him to visit and be with his mother. The brother had a range of reasons for not responding to the call to gather around. The family found their brother’s behaviour unacceptable. The family saw their mother as needing him to visit so she would have the opportunity to say good-bye to all her children. The female Māori informant acknowledged that her brother may not have understood his role as a son. He came to the house a few days before their mother died.  The adult children and grandchildren of Informant 2 came as often as possible. | Angelo (2014)9, New Zealand | 85 | Informant 1: Māori, female  Informant 2: Māori, male |
|  | Identified stressors for all groups mirrored common stressors found in the literature, including: transportation difficulties; medication management; difficult learning curve for symptom changes; assisting with toileting, bathing, and other ADL’s; family problems related to patient care; lack of sleep; lack of help, services, and respite. | Anngela-Cole (2011)10, United States of America | 328 |  |
|  | The major cultural differences in acknowledging sadness had to do with losses related to comfort and traditional food, versus losses related to participation in events and spending time with family and friends. The Native Hawaiians expressed deep sadness at not being able to be a part of family gatherings, where there was much traditional Hawaiian food, lots of family members (beach park gatherings), and talking with friends.... All of these events, from inability to eat, to lack of participation in family gatherings, were reported in the context of things that were identified as profound sadness or loss, rather than inconveniences of providing care. Therefore, they are included here as identifiers of anticipatory loss. | Anngela-Cole (2011)10, United States of America | 330 |  |
|  | “It is the family [caregivers] that takes care of them day in and day out, so they see a lot of things going on there. With my uncle ... [he was] up at all hours of the night and [I saw] how uncomfortable he was and the pain he was in. Those are the kinds of things ... witness ... however in my position you see the individuals. I have gotten to know them very well. Watch them struggle with their condition.” | Hodge (2016)5, United States of America | 225, 226 |  |
| This multipurpose role of the caregiver was described as a rewarding, yet a distressing job. With little or no training, the caregiver looked after the daily needs of the patient, while observing a decline in health. One caregiver said, “I am having a hard time with this ... helping people, working with people fighting for their life.” Another said, “I have gotten to know them very well. Watch them struggle with their condition.” Other caregivers mirrored these sentiments, “Then that year, [I] come to know [the patient’s] experience and to see her day in and day out, knowing her good days and bad days. ... 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.” | Hodge (2016)5, United States of America | 225 |  |
| The majority of participants, 23 of 26 (88 percent), reported that they were challenged to help their husbands stay focused on health and living; to accommodate changes in the marital relationship, especially with regard to sexual intimacy; and to appreciate the positive in their life, despite uncertainty and loss. | Ka’opua (2005)14, United States of America | 148- 149 |  |
| **Culturally unsafe health systems and settings** | | | | | |
|  | **Complex and alienating health system** | | | | |
|  |  | The respondents who expressed dissatisfaction often discussed the delays due to conflicting regulations between cancer care providers and primary care providers, as described by this caregiver, “The rules and regulations between, like I said, Indigenous health service, (primary care provider), and the oncology...I think her most challenging [experience] was definitely when it came to...trying to realize the rules of each of the programs.” When asked what made the cancer care experience more difficult, another caregiver explained, “I think the communication between IHS and Contract Health (care provided away from IHS) and the oncology... just having the doctors complete the applicable paperwork in order for her to get the prescription filled [was difficult].” | Hohl (2016)1, United States of America | 2441 |  |
|  |  | Care coordinators provided an opportunity for patients and their carers to deal with a single person, instead of having to manage multiple providers. As explained here: “Our head’s not even screwed on, we’re not thinking straight. We’d rather deal with 1 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. Where in [Interstate hospital] it was-we had 10 million people coming in and introducing themselves and giving us cards. I’ve got a purse full of cards from [Interstate hospital], don’t know who they are.” | Reilly (2018)11, Australia | 932 | Aboriginal carer 4 |
|  |  | Another recurring theme raised by Aboriginal people was the need to have Aboriginal support people among the health care team - simply the inclusion of Aboriginal people in the health care team would equate the service as being more welcoming. Participants spoke of how alienating and disempowering the hospital environments was for Aboriginal people, with them often lacking the confidence to speak up. The health care team was seen as only treating the disease and not adapting the model of care to suit Aboriginal patient: “they want us to fit into their culture. They want to take us from our box and put us in their box.” | Thompson (2011)13, Australia | 5 | Urban, female family member |
| Low literacy was acknowledged as another challenge observed by participants, even when it didn’t directly impact upon them. For example, one participant described that although she felt she was okay because she could read, it was difficult for others without these skills. She considered that hospital staff were often unaware of these challenges: “... you know some of the elders and some young people who are stressed out and walking around trying to find B block or whatever, the radiation centre, yeah; it’s hard. If the line is not there or the name is not there, you can’t find the place. This is the hospital.” | Thompson (2011)13, Australia | 3 | Urban female family member |
| Many participants reported their frustration with delays in the hospital system. Given the aversion that most people expressed to being in hospital, their distrust of them and desire to return home to family and country, delays in treatment and discharge were considered particularly significant. | Thompson (2011)13, Australia | 4 |  |
| The alienating environment reported by most participants was felt most acutely by those from rural and remote areas and contrasted with their sense of belonging in the bush and close bond to country. The sheer size of cancer treatment services in tertiary hospital settings was unfamiliar and overwhelming to people from rural and remote areas and created difficulties: “The first time they have probably even been to Perth [capital city of Western Australia] is to go down to a big square hospital, a big cement building. Is it any wonder they die?”. Another participant described the hospital as one big grey building stating that “We were just about crying and so was he [my dad]. He wanted to get back to the bush.” | Thompson (2011)13, Australia | 3 | Rural female family member |
| **Family-focused care** | | | | |
|  | Informant 1 and her family chose to care for their mother in the sister’s home because it was the largest. Informant 1 described her family as urban Māori: “We eat, cook, and sleep together.” This informant was able to take her family and live in her sister’s home because she was home schooling her two young children. Her husband visited on the weekends. With tasks divided among the sisters, the informant became the laundress and the informal nurse, managing her mother’s medications. Another sister was in charge of personal care. Cooking was divided between another sister and one of the husbands.  The family of Informant 2 visited frequently, and the family lived together the last two weeks of his wife’s life. | Angelo (2014)9, New Zealand | 86 | Informant 1: Māori, female |
|  | Informant 1 had the largest number of family members involved in caregiving activities. When the family physician said her mother most likely would not live more than three months, the family decided to live together in the home of the sister of Informant 1. They moved their mother from her apartment to this home. The informant moved her family there to be with her mother. Altogether, there were three sisters and one husband living in the house, and the other two husbands came as frequently as possible after work. Routines quickly evolved, with each sister taking on occupations they found most rewarding and felt most capable of performing with confidence. According to Informant 1: “So with us girls and our children we allocated each other work, like who was going to do the washing, who was going to do the cooking, who was going to look after Mum. I became chief caregiver of Mum because what was happening, the girls found it difficult seeing Mum deteriorate, like seeing [her] not take her medicine well. I found it difficult too, but me being the oldest, I thought, ‘OK, I better suck it in and do this.’ The ones that I thought were stronger couldn’t do that area. One of the sisters ended up doing the bathing of Mum because she didn’t trust me because I’m such a gentle person. I was scared I was going to break her because she was very fragile, and she kind of looked at me like, ‘You’re not going to bathe me.’ So we got one of the other girls to bathe her, and she’s fantastic. They have muscles, and they know how to rattle Mum up. My other sister had a really important job and she needed to go to work, and she would relieve us in the night. We were able to give each other rests. I slept in the same room as Mum so I could hear anything. One of my sisters slept in the room next door, if I fell asleep and couldn’t hear. We gave Mum a bell because she couldn’t speak, so she would ring the bell if she needed anything”. | Angelo (2014)9, New Zealand | 84, 85 | Informant 1: Māori, female |
|  | One whanau member went further to state: “The whānau needs to know, to have a clear explanation of what hospice services…not provides but wraps the family in... They need to know, to ensure that the whānau fully understand, not just give them this verbatim stuff and it goes over the top of the whānau head and then they have to try and remember ‘oh what did they say’?” | Frey (2013)6, New Zealand | 523 | Maori bereaved family member |
|  | Survivors and families generally felt that they did not get enough information from the physician, in part because they were too intimidated to ask the questions. Families felt that the physician was patient focused rather than family focused. | Mokuau (2007)8, United States of America | 193 |  |
| The problems encountered in hospitals were in contrast to that described by one participant who was appreciative of the arrangements of a particular hospice and how it embraced family involvement: “They supported us as a family in every way. For if we wanted to stay over, we could stay over. They have got a kitchen...every family member of the patient ... they could use that any time day and night, 24 hour services. There was no restriction. All you have to do is go and ring the bell at 2 o’clock and you are in... and my family in the last two weeks of her life basically lived there and had rosters off. She was never left alone.” | Thompson (2011)13, Australia | 4 | Urban, female family member |
| **Mistrust and experiences of racism** | | | | |
|  | The reported barriers to institutional support extended beyond geography and economics. In urban settings with more resources, participants criticized the lack of respectful care for First Nations patients. Both survivors and caregivers stated they had received differential treatment, which perpetuated their silence and limited their access to care. For example, to some, support groups seemed uninviting and spaces where “white women could only go”. Although relationships with health care professionals varied, it was generally recognized that First Nations peoples do not have equitable access to care. | Hammond (2017)4, Canada | 194 | Survivor of breast cancer |
|  | Mistrust of the health system was commonly expressed by participants and recognized as a barrier to accessing health services. “… a lot of them get scared when they go into hospitals because when family members go into hospital all they do is die because they wait at home for so long before they go and see a doctor…” | Reilly (2018)11, Australia | 933 | Aboriginal carer 13 |
| Racism was viewed as a barrier to Aboriginal people accessing health services at all: “…a lot of people won’t speak up because they don’t want to go through all that rigmarole of the name calling and all that sort of stuff…so they shut up, they stay quiet and they don’t talk unless it’s to one of their own…they know is going to listen.” | Reilly (2018)11, Australia | 933 | Aboriginal carer 14 |
| Participants (both Aboriginal and non-Aboriginal) reflected that for Aboriginal Australians, a collective experience of racism and marginalisation has led to widespread distrust of institutions of mainstream society, such as health care. Tanya described ways in which fear or mistrust of the health system can be directly linked to decisions about engaging or avoiding cancer care. “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” | Treloar (2014)7, Australia | 376 | Non-Aboriginal carer |

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