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Experiences with health information among caregivers of people with cancer from culturally and linguistically diverse backgrounds: A qualitative study

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Abstract

Objectives. Although some research suggests that caregivers from culturally and linguistically diverse (CALD) communities have higher unmet information needs compared to their English-speaking counterparts, few studies have examined determinants of information needs among CALD cancer caregivers and their satisfaction with received information. This study aimed to explore experiences with cancer-related information among caregivers of people with cancer from CALD communities.

Methods. Semi-structured interviews were conducted with 24 caregivers from Arabic and Chinese backgrounds (12 in each group). Thematic analysis was used to analyze data.

Results. Participants' mean age was 40.6 years, and most were female (83%). Six themes were identified: (a) lack of information to meet their needs; (b) challenges understanding cancer- and care-related information; (c) proactivity to make sense of, and understand information; (d) interpreting information: the role formal and informal services; and (e) engaging with health providers to access information.

Conclusions. Caregivers identified significant language and communication barriers impacting their capacity to understand cancer-related information given by providers and they invested personal effort clarifying information. The importance of access to formal interpreter services, even when caregivers and care recipients seem proficient in English, was highlighted. Cultural sensitivity of providers when discussing a cancer diagnosis and treatment was also identified as an important consideration.

Significance of results. Culturally tailored outreach programs designed to provide key cancer-related information which are accessible to CALD caregivers have the potential to improve the health outcomes of both caregivers and care recipients.

Cancer is a major cause of illness and death globally, accounting for 9.9 million deaths worldwide in 2020 (Sung et al. 2021). In Australia, cancer accounted for almost 30% of deaths in 2020 (Australian Institute of Health and Welfare 2019). There is recognition that family members and friends (i.e., informal caregivers) play a key role in providing necessary practical, physical, informational, and psychosocial support across the disease trajectory for people diagnosed with cancer (Sun et al. 2021). Caregiving can be rewarding, although the significant emotional impact of being a cancer caregiver has also been recognized (Kent et al. 2016; Shaw et al. 2013a). Caregivers are vulnerable to physical and emotional exhaustion, feelings of ill-preparedness, and persistent levels of anxiety and distress that are higher than that of the general population (Shaw et al. 2013b). They are often tasked with managing the care recipient's symptoms, side-effects of treatment, and physical decline, alongside juggling competing duties, and managing their own emotions about the cancer and the unpredictability of the future (Janda et al. 2008).

Access to adequate cancer- and care-related information across the cancer trajectory has been associated with improved health-related quality of life for care recipients (Høeg et al. 2021) and improved psychological well-being for caregivers (Møller et al. 2020). However, caregivers frequently report unmet needs related to accessing comprehensive information about the diagnosis, the health system, treatment options, and how to manage at-home care when providing support to someone with cancer (Sklenarova et al. 2015; Wang et al. 2018). Caregivers have described obtaining cancer-related information largely from health-care providers but also needing to dedicate significant amounts of time

to researching information through channels including charities, the Internet, and peers (Kinnane and Milne 2010; Morris and Thomas 2001).

People affected by cancer from culturally and linguistically diverse (CALD) backgrounds, described as those who speak a language other than the predominant language of their residential country, have been shown to have higher unmet information needs compared to their English-speaking counterparts (Butow et al. 2013). Caregivers from CALD communities have identified additional language, cultural, and communication barriers that negatively impact their capacity to communicate with, and access information from, providers. A qualitative study with patients and caregivers from CALD communities that explored experiences of transition to palliative care found communication challenges involving difficulty understanding the meaning of words that did not directly translate to their language (e.g., “palliative”) (Kirby et al. 2018). Difficulty discussing pain management without an interpreter was also identified (Kirby et al. 2018). Similarly, a recent study of Arabic people with cancer and their caregivers found carer challenges understanding cancer-related information given by providers, as well as those presented in written format (Alananzeh et al. 2019).

Research on the information needs of people affected by cancer from CALD communities has emerged (Alananzeh et al. 2019; Lambert et al. 2021; O’Callaghan et al. 2016; Wiley et al. 2018); however, few studies have examined the information needs of caregivers of people from CALD backgrounds (Schaffler et al. 2019). To date, there exists a dearth of literature that examines the information needs of caregivers of people with cancer residing in Australia. Given that over 1 in 4 people in Australia was born in a foreign country (Australian Bureau of Statistics 2021a), there is a need to better understand their information needs and how these can be addressed, in a cancer context. Thus, the current study focuses on caregivers of people with cancer from an Arabic and Chinese background, as these are 2 of the largest language groups residing in Australia (Australian Bureau of Statistics 2021b). The aims of the study were to qualitatively explore experiences with cancer-related information among caregivers of people with cancer from CALD communities.

Method

A qualitative design comprising semi-structured interviews was used to explore carers’ information needs. Eligibility criteria for participants included those who (a) were currently providing, or had provided, unpaid care to someone diagnosed with cancer (i.e., the care recipient), and whose care recipient spoke Chinese or Arabic as a first language, (b) were age 18+ years, and whose care recipient was 18+ years, (c) had provided care to the person with cancer within the preceding 3 years, and (d) were able to speak English without an interpreter. The study received ethics approval from the La Trobe Human Research Ethics Committee (HEC20465).

Data collection

Participants were recruited by the LOTE Agency, a Melbourne-based market research agency. Eligible participants were sent a consent form by LOTE and were then contacted by the researcher to arrange an interview via teleconference (Zoom). Verbal consent was sought at the commencement of each interview, and interviews were audio-recorded. A semi-structured interview schedule was

used to guide the interview. Participants were asked about the emotional impact of caring, and the kinds of informational support they had needed and/or accessed. Interview length ranged between 25 and 75 minutes. Data were collected between March and May 2021. All participants were given copies of their transcript for review.

Data analysis

Interviews were transcribed using Otter.ai transcription software. To ensure transcription accuracy, a researcher listened to each interview in full and corrected errors. To protect confidentiality, all participants were allocated a pseudonym. Braun and Clarke’s (2006) 6-phase process of thematic analysis was used to analyze the data. The study utilized an exploratory, “data driven” approach, where codes arose from the data, as opposed to pre-determined questions or theory (Braun and Clarke 2006). Two researchers (MH and EY) familiarized themselves with the data through reading and re-reading the transcripts. A systematic approach was used to code all interviews. Codes were then grouped into potential themes, with constant comparisons with existing data to ensure relevance and accuracy in capturing meaning across the data. The research team reviewed and confirmed resultant themes through discussion. Meaning-making and insight into participant experiences were gained through applying an iterative, reflexive, and immersive process when examining the data. Researchers sought to maintain reflexivity by positioning themselves as a learner, and participants as the experts in their lived experiences, in addition to adopting the view the research was being conducted in partnership with participants (Berger 2015).

Results

Participant demographic information is shown in Table 1. Participants were aged on average 40.6 years (range 29–65; 3 participants did not report their age). Half the sample ($n = 12$) were of Arabic background, and the other half ($n = 12$) were of Chinese background. Majority of caregivers (83%) were female. Over one-third of participants provided care to a parent (41.67%).

Six themes related to caregiver experiences with health information emerged from the analysis: (a) lack of information to meet their needs; (b) challenges understanding cancer- and care-related information; (c) proactivity to make sense of, and understand information; (d) interpreting information: formal and informal services; and (e) engaging with health providers to access information. Quotes to support the themes and sub-themes are presented in Table 2.

Lack of information to meet their needs

Caregivers identified a range of unmet information needs across the cancer trajectory. Participants identified unmet information needs at the start of treatment, when they managed the shock and uncertainty of the patient’s diagnosis. Furthermore, some participants found that health-care providers communicated information too slowly across all stages of treatment, which exacerbated their worry. Other caregivers also identified unmet information needs related to treatment options and decision-making for the care recipient. Unmet information needs related to how to best provide care to the care recipient. This included managing food and diet. Information about the patient’s emotional needs including advice for managing their feelings, health anxiety, and difficult

Table 1. Participant demographics

Caregiver	Group	Age	Gender	Care recipient was my:	Care recipient cancer type
1	Chinese	30	Male	Mother	Kidney
2	Chinese	29	Female	Mother	*
3	Chinese	35	Male	Grandfather	Stomach
4	Arabic	35	Female	Husband	Colon
5	Chinese	30	Female	Stepfather	Brain
6	Chinese	29	Female	Sister	Cervical
7	Chinese	*	Female	Aunt	Stomach
8	Arabic	35	Female	Husband	Thyroid
9	Chinese	*	Female	Cousin	Prostate
10	Chinese	28	Female	Mother	Head and neck
11	Chinese	44	Male	Father	Gastric
12	Arabic	51	Female	Daughter	Hodgkin's lymphoma
13	Arabic	*	Female	Mother	Bladder
14	Chinese	28	Female	Friend	Cervical
15	Chinese	31	Female	Mother	Leukemia
16	Chinese	29	Male	Grandmother	Pancreatic
17	Arabic	54	Female	Daughter	Thyroid
18	Arabic	65	Female	Daughter	Non-Hodgkin's Lymphoma
19	Arabic	55	Female	Mother-in-law	Leukemia
20	Arabic	24	Female	Mother	Breast
21	Arabic	55	Female	Mother-in-law	Pancreatic
22	Arabic	56	Female	Sister	Ovarian
23	Arabic	49	Male	Father	Kidney
24	Arabic	62	Male	Wife	Breast

*Unclear/not provided by participant.

behavior was also required, and some indicated struggling to find appropriate guidance.

Challenges understanding cancer- and care-related information and unmet information needs

Although some caregivers reported satisfaction with information given by health providers, other caregivers reported difficulty understanding the cancer-related information they were given. (Table 2). The lack of understanding of cancer-related information was attributed to not having a background in medicine.

Proactivity to make understand information and build knowledge

Despite being able to speak English to varying levels of proficiency, caregivers in the study identified that difficulties with English impacted their ability to understand information and, consequently, had to invest significant effort making sense of information outside of appointments. Participants engaged in a number of strategies to ensure they could understand cancer-related information and to build knowledge. These strategies included: (a) searching for information online, (b) conferring with other sources to

understand cancer-related information; and (c) writing questions in advance of appointments. These knowledge building strategies are described in the following sections.

Searching for information online

A number of caregivers described the challenge of not understanding cancer-related information during appointments, and to overcome this, they searched online to understand issues discussed during meetings with health providers. Caregivers contended that information provided in a second language was difficult to comprehend, particularly specialist medical terms. To overcome the language barriers, caregivers would search for medical term they had heard during medical appointments and translate these into their first language – Chinese or Arabic. Caregivers also spoke of asking the doctor to document English-language medical terms so that the caregiver and care recipient could search online for the meaning. Further, 1 caregiver stated that doctors and health services could not provide all the necessary information, and that it was the responsibility of the family members to seek cancer-related information online to support the care recipient.

Several caregivers discussed seeking information online about cancer as a means to reassure the care recipient of potential positive

Table 2. Supporting quotes for themes and sub-themes

Themes/sub-themes	Supporting quotes
Unmet information needs	
	<p>“we would have appreciated more support [in the beginning]. ... More people coming and explaining what they're doing.” (C12, Arabic, female, caring for daughter)</p> <p>“... they're so slow [with providing information]. We're anxious, we want to know: when's the surgery?” (C6, Chinese, female, caring for sister)</p> <p>“... [need more advice] about his food, about what he has to eat ... what you have ... don't have to eat ... avoid food, or what he has to do if he goes to work after his operation.” (C4, Arabic, female, caring for husband)</p> <p>“I don't know the information. Yeah, I don't know who to ask ... [about] what ... medication should be useful and how much they cost? And yeah, like, if it's, it can be applied to my mum's disease?” (C10, Chinese, female, caring for mother)</p> <p>“... [I wanted to know the] way I need[ed] to talk and the things I need[ed] to say ... because at the beginning, my cousin always get angry with me.” (C9, Chinese, female, caring for cousin)</p>
Challenges understanding cancer- and care-related information	
	<p>“... they've been talking about, like, this stage [of disease]. But I couldn't comprehend ... what does that mean? They've got stage one, stage two, stage three? What does that mean? I think it's because my lack of knowledge. I did look into things a lot, but I don't have a medical degree.” (C6, Chinese, female, caring for sister)</p>
Proactivity to make sense of, and understand information	
Searching for information online	<p>“... the first time [the information was given to me], it's very hard understand, then I make a search.” (C4, Arabic, female, caring for husband)</p> <p>“we found a lot of ... terms that we didn't get it, so I had to ... Google it and see the translation for it.” (C12, Arabic, female, caring for her daughter)</p> <p>“for the simple things we can understand and for the professional things we just Google to know the Chinese meaning ... the doctor write down the professional word, and we just Google and we know what that meaning.” (C9, Chinese, female, caring for cousin)</p> <p>“... if you're a relative you must search the knowledge online. I think that if your, your relative got cancer, you cannot count on a doctor or hospital totally. I think possibly just the one third I even did the plenty of research online. So I explained to my dad, you got a huge percentage opportunity to be recovered. Yeah, for the last two years, we're always encouraging” (C11, Chinese, male, caring for Father)</p> <p>“... don't know what's going to happen. [You just think] it's cancer, [they are] gonna die But then once we did more research and talk to doctors and friends [then you know more]” (C14, Chinese, female, caring for friend)</p>
Conferring with other sources to understand cancer-related information	<p>“Doctor, give me a little bit [of information], and I come back at home, I try to calculate everything ... ask other people” (C4, Arabic, female, caring for husband)</p> <p>“... [the doctor] shared it with me, but I had to like ... teach myself. And I actually called the GP wanting to know ... like to understand.” (C8, Arabic, female, caring for husband)</p>
Implementing strategies to understand the care recipient's health	<p>“... there was a small board in my mum's room, saying what is her data that day I'll check the data and ... if I get a chance, also speak to a doctor.” (C15, Chinese, female, caring for mother)</p> <p>“I have the copy of all ... the blood test results, urine test result, and the size of the tumour I plot line graph ... to analyse if she's getting better or not.” (C1, Chinese, male, caring for mother)</p> <p>“I literally have a note of what the question I want to ask. ... Whenever I see a doctor, I just ask all the questions.” (C12, Chinese, female, caring for friend)</p>
Interpreting information: Formal and informal services	
Challenges with accessing, and quality of, formal interpreter services	<p>“It was good and they will always make sure that there is like an interpreter and she's on time” (C20, Arabic, female, caring for mother)</p> <p>“maybe it's because I'm always around, so the hospital doesn't really offer ... a translator.” (C6, Chinese, female, caring for sister)</p> <p>“I understand if we would like to request interpreter we can. However, the doctors they come and visit, they wouldn't tell us, when they would come visit, my mom would just be in the room in the hospital ... and sometimes [with an] interpreter they book it but they didn't show up most of the time.” (C15, Chinese, female, caring for mother)</p> <p>“Sometimes ... I understand the doctor, but I couldn't answer him. But when the interpreter ... translate, they ... don't told you the exact sentences what the doctor say” (C13, Arabic, female, caring for mother).</p> <p>“To find the translator on time is, is normally we're on the queue or, or the translator is not available. So yeah, sometimes my aunt will be really, really worried about ... yeah, so, so the comfort didn't arrive on time ... waiting for the translator, and wait for a result or someone can clearly explain what, what she should do to release her pain ... because some terminology is very hard to communicate.” (C7, Chinese, female, caring for aunt)</p> <p>“... not all caregivers have good English level. So definitely, [interpreters] will help them a lot when communicating with the doctors or nurses to avoid some misunderstandings I think if we, if we need to translate. Need to hire someone ... out of our pocket.” (C16, Chinese, male, caring for grandmother)</p>

(Continued)

Table 2. (Continued.)

Themes/sub-themes	Supporting quotes
Caregiver as interpreter and information source for patient	<p>“... when she was in hospital, I stayed with her ... and when the doctor needs something, or some details or some information from us, so I’ll also communicate with doctor as well, or nurses.” (C15, Chinese, female, caring for mother)</p> <p>“... So I think they ... they rely on me during the communication with doctors and nurses because of the English level I have I mean, when it comes to taking care of patients, everybody should have the same duties trying to make the patient happy I believe for those medical terminologies a little bit. Even in my mother tongue, it’s ... challenging for me.” (C16, Chinese, male, caring for grandmother)</p> <p>“I’m not allowed into the room, but I just translated some ... [and] I think I’ve missed some information I can’t imagine how ... nervous my aunt went into the room after, by herself.” (C7, Chinese, female, caring for aunt)</p> <p>“... when she had cancer she shocked. Then when the interpreter talking, I feel like she didn’t concentrate She depends on me ... she asked me many questions ... sometimes it’s hard, yeah is really hard. Because like you explained to her, and it’s very simple way. Again, she came to ask you second day, or after one week, the same question.” (C13, Arabic, female, caring for mother)</p>
Caregiver as gatekeeper of information when interpreting to the care recipient	<p>“So I try to ... not to tell directly, but still give ... still give her some hope I wouldn’t say the doctor ... give up already. So yeah, I would say they said just stay in the hospital taking the normal ... taking the treatment, medical treatments as usual. And you will be fine Because I heard some news on social media, or news ... sometimes keeping positive in mind may be a cure to the cancer, so ... why not try that.” (C16, Chinese, male, caring for grandmother)</p> <p>: “... like I know she’s my mother-in-law, but it’s very hard for me to tell her. You only have a few weeks to live ... it’s spread all over the body [but] we just like try to say, oh, it’s just growing little bit. It’s not as tall as before. So those kinds of things like we tried to hide the serious things from here.” (C21, Arabic, female, caring for mother-in-law)</p> <p>“... at first, I feel the need to translate every word, even the tiniest word. I want her to know everything. And then after a while, I start to filter information. Which I think might be good for her, but maybe it’s just me being selfish because she can be very emotional, and I understand, because ... she’s freaking out. And I am freaking out as well. And I think it’s ... three months after her diagnosis, I started to get a bit impatient ... maybe the conversation is a minute long, and I will tell her in like one sentences and then she will freak out And I have to explain to her and then she’s just getting paranoid and be like, ‘why are you lying to me?’, and I’m like, no I’m not lying to you. Why would I? And yeah, that kind of stuff happened a lot.” (C6 Chinese, female, caring for sister)</p> <p>“... due to the different culture or, or not, because we normally don’t tell the patient herself what kind of disease she got ... we are normally avoiding to let the patient herself know about the serious outcome or just to worry too much to influence her emotions I think Chinese people are more like, trying to keep the patient in a happy and the positive attitude.” (C7, Chinese, female, caring for aunt)</p>
Engaging with health-care providers to access information	
Communication with health-care providers	<p>“... [the doctor] did speak with me He said she ... should [go ahead with] chemotherapy ... to stop the cancer growing He like feel like, make me confident. I feel more relaxed He supports me, the doctor supports me Because in Iran, when you hear somebody, he has a cancer, you think most of them, they die. Because no, we don’t have like, our money to pay for the treatment for the chemotherapy. That’s why then, but when the doctor explained to me here ... [treatment is] free. He’s very kind [and] explained everything for me, even I don’t have English in that time. And I just like to speak a few words. And he answer me” (C13, Arabic, female, caring for mother)</p> <p>Another caregiver shared that providers used easy to understand language to facilitate comprehension: “... they use simple English with me ... no Arabs there, but they used simplified English” (C8, Arabic, female, caring for husband)</p> <p>“... We’re anxious, we want to know when’s the surgery? And how, how is ... how is everything, and we don’t really know a lot about cancer. And yeah, they, I believe they try their best to explain, but um, and they’re really busy, but they just don’t really have ... um, explain enough” (C6, Chinese, female, caring for sister)</p> <p>“Yeah, maybe like, need more advice from the doctor? Because we ask all the time ... he said ‘everything I have pain here and I have pain here.’ And he went to ... and the doctor said ‘maybe you need like some supplements, that’s good for him.’ But we will have ... we would like to have more advice.” (C4, Arabic, female, caring for husband)</p>
Caregiver capacity to ask questions and seek information from health-care providers	<p>“... Yeah, if I didn’t understand ... something I asked them to do is to explain in an easier way.” (C16, Chinese, male, caring for grandmother)</p> <p>“[The care recipient] can speak fluent English as well But he just for some professional questions, he cannot ask. Yeah, so we need to Google or find the answer ourselves but most of time we just write down this word to the doctor, doctor know what that meaning word, we want to ask.” (C9, Chinese, female, caring for cousin)</p> <p>“... so there’s things I just, I just can’t understand and I, I felt stupid to ask, what does that mean, what is this thing? It’s like, the doctors giving me like a medical school lessons and stuff like that. So I wouldn’t want to bother them.” (C6, Chinese, female, caring for sister)</p>

(Continued)

Table 2. (Continued.)

Themes/sub-themes	Supporting quotes
Cultural sensitivity and directness of providers when discussing cancer-related information	<p>“I think that the doctor and nurses may communicate more based on the truth, and the health conditions are the cancer patient, if it's bad, or if it's um, if it's, really bad or if it's at the early stage of the cancer ... they just tell us what the truth is. But we need to refine the sentences ... when we deliver it to the patient.” (C16, Chinese, male, caring for grandmother)</p> <p>“... In my country, like, the Middle East, they don't say directly, you have a cancer There's a big difference [in Australia]. I think ... it's ... painful if you say to the patient 'you ... have cancer' directly ... maybe you have to tell the friend first or family first. If the patient comes to the doctor with someone like you have to tell the [other person] first, and then you have to tell the patient, you know what I mean? ... sometimes don't tell [the patient] directly.” (C4, Arabic, female, caring for husband)</p> <p>“... in China. doctor would rather tell family member first and let family member to decide whether to tell patient or not ... if all the family members encouraged doctor not tell my Grandfather [that he has] stomach cancer, [the doctor] will not tell directly to my Grandfather. Unless my grandpa made a direct phone call to him, because you know the doctor cannot tell lies, he just not directly tell Grandfather ... for each appointment, [the doctor] said you should do this you should do that, and you should take care and just eat this medicine, something like that. He will not [tell the patient] you have cancer, stomach cancer” (C3, Chinese, male, caring for grandfather)</p>
Preference for same language health-care providers	<p>“... the GP is Arab and the surgeon was Arab too, so ... they won't speak English.” (C8, Arabic, female, caring for husband)</p> <p>“I feel very comfortable because the language [and] communication like each other ... if we see [an English-speaking] doctor, if they say 10 sentences, maybe I just get another eight sentence but another two ... because they have the word I don't understand. Maybe I couldn't get it after the eighth sentence But if they speak Chinese, so even I don't know what that meaning, but 100 percentage meaning I can get ... [with English-speaking people] ... I need to listen hard to get the information, absorb the information by myself.” (C9, Chinese, female, caring for cousin)</p>

outcomes following cancer treatment. Another caregiver spoke of seeking information online about the prognosis to support well-being of the care recipient.

Conferring with other sources to understand cancer-related information

Although caregivers reported that doctors provided information about the cancer, they also sought clarification about the information supplied from other sources. Caregivers spoke of clarifying information with people in their social networks. One caregiver described contacting their General Practitioner to help them understand information about the cancer.

Implementing strategies to understand the care recipient's health

Even when language did not present a barrier, participants went to considerable effort to understand medical terminology and the patient's condition (Table 2). One participant closely monitored the care recipient's medical charts and conferred with health providers. Another participant would analyze the care recipient's test results to track prognosis and potential outcomes. Some participants also prepared questions for the next time they would speak with a doctor.

Interpreting information: Formal and informal services

In describing the role of formal interpreter services, as well as the caregiver's role in informally interpreting information, 3 sub-themes emerged: (a) challenges with accessing, and quality of, formal interpreter services; (b) the caregiver as interpreter and information gatekeeper, and (c) caregivers filtering information when interpreting to the care recipient. These sub-themes are captured below.

Challenges with accessing, and quality of, formal interpreter services

Caregivers' experiences with hospital interpretation services were mixed. Some participants were offered an interpreter, while other participants reported that hospital staff did not offer them access to formal interpreter services or could not recall if they had been given the option. For some caregivers, positive experiences were reported when health services ensured interpreters were available for the care recipient. However, other caregivers reported that health services did not identify a need for interpreters for the patient if the caregiver appeared to have a strong grasp of English. When interpreter services were offered, participants reported difficulty coordinating services with the schedule of doctor's visit in the hospital room or stated that interpreters did not attend the scheduled appointment. When interpreter services were available, 1 participant reported the interpretation could be inaccurate.

Lack of access to an interpreter impacted care recipient's quality of life, with 1 caregiver describing circumstances whereby neither they nor the patient could understand information about pain management since medical terminology was beyond their scope. Indeed, 1 caregiver identified interpretation as the main service hospitals could provide to better assist caregivers. Another caregiver assumed interpreter services would incur an out-of-pocket cost and, therefore, did not seek these services.

Caregiver as interpreter and information source for their care recipient

Many participants acted as an interpreter for the care recipient, relaying information between providers and the person with cancer. Some participants appeared to accept interpreting as their caregiving duty without question. However, caregivers also identified challenges when interpreting information for the care recipient. One participant reported anxiety about mistranslating information. Additional challenges included not being able to access

all appointments or hospital areas, with this restricted access constraining caregivers' capacities to interpret information for the care recipient.

Caregivers also described their role as an information source for the care recipient: they "recapped" cancer-related information for the care recipient. In this instance, although interpreters were available, the care recipient was unable to absorb information given to them and relied on the caregiver to repeatedly explain cancer-related information, which was a burden for the caregiver.

The caregiver as gatekeeper of information when interpreting to the care recipient

Several caregivers reported acting as gatekeepers of the information supplied by health-care providers when interpreting for the patient. For some caregivers, this was a protective factor, to support the maintenance of hope in the care recipient. The maintenance of a positive outlook by the patient was seen, by 1 caregiver, as critical to achieving an effective treatment outcome. Non-disclosure of the full details of the cancer diagnosis to the patient was considered protective of the care recipient's emotional well-being, avoiding the loss of hope.

For other caregivers, acting as a gatekeeper of information appeared to be a strategy to avoid giving bad news to the person with cancer. Another participant reported filtering information to protect the patient from experiencing psychological distress and anxiety; filtering information was also used as a coping mechanism for themselves to manage their own frustration and anxiety about needing to interpret all the information.

Engaging with health-care providers to access information

Communication with health-care providers

The quality of the caregiver experiences when communicating with health-care providers to get information was mixed, with some caregivers reporting positive and others reporting negative experiences. Positive experiences included reports that providers made it easy to understand cancer-related information. One caregiver spoke of providers who explained treatment processes to the caregiver and the care recipient to enable them to understand potential health outcomes. Other caregivers reported that providers spent considerable time with the caregiver to help them understand that cancer is not an automatic death sentence and the affordability of treatment options available for the care recipient.

However, other caregivers reported wanting more information from health providers. Some caregivers spoke of not receiving enough information from providers about the cancer or the treatment process thereby exacerbating their distress. Other caregivers spoke of wanting more tailored advice to manage the care recipient's discomfort while on treatment.

Caregiver capacity to ask questions and seek information from health-care providers

Caregivers' capacity to ask questions of health-care providers in order to get the information they sought was mixed. Some caregivers were confident they had the skills to ask health providers to explain information in another way if they did not understand in the first instance. One caregiver spoke of writing down words in advance to ask the doctor to explain during interaction. However, other caregivers did not want to bother providers with their questions and believed asking questions about information they didn't understand during an appointment would reflect poorly on them.

Cultural sensitivity and directness of providers when delivering cancer-related information

Cultural difference in preference for directness in communication with health-care providers was an issue raised by some caregivers. Several participants reported that it would be uncommon in their country of origin for providers to directly inform a patient that they have cancer and spoke of the need for sensitivity among providers when sharing cancer-related information with the patient and care recipient. Caregivers also reported that in their home country, doctors would disclose the cancer diagnosis to family members, rather than the patient themselves. Furthermore, caregivers described health providers in their home country as respectful of the person with cancer's family members and their desire to disclose or hide the cancer diagnosis from the patient.

Preference for same language health-care providers

Caregivers identified the usefulness of having providers who spoke their native language. One caregiver described working with health providers who also spoke their native language and highlighted how this helped with the patient and carer understand information. One caregiver spoke of their preference for access to first language health providers as a means of facilitating ease and comfort with communication.

Discussion

The present study aimed to explore experiences with seeking and receipt of health information among caregivers of people with cancer from CALD communities residing in Australia. Although participants were generally satisfied with information given by providers, they also reported difficulty understanding the information, and many implemented a range of strategies to understand the care recipient's diagnosis and treatment. Our findings are consistent with previous studies in which it has been suggested that caregivers from CALD backgrounds have additional unmet informational needs (Kirby et al. 2018; Lim et al. 2019; Shaw et al. 2016). Information needs were high at diagnosis and during treatment; caregivers wanted more information about processes and what to expect. Caregivers identified spending significant time and effort to seek and understand information outside of appointments with providers to build cancer-related knowledge. Findings highlighted the importance of health providers allocating enough time for caregivers to ask questions, record medical terminology for translation, and explain concepts that do not directly translate to attenuate the language barrier.

Caregivers in the current study reported that interpreter services were not often available or offered. Additional challenges were identified during in-patient stays where appointments and provider consultations did not involve adequate notice to organize an interpreter. Indeed, participants highlighted the need for consistent and timely interpreter services, and for providers to arrange these services, even for unscheduled hospital visits from doctors. Given the challenges identified by caregivers when understanding information, even for those with adequate English proficiency, advanced planning to ensure access to formal interpreters during patient-provider interactions would likely benefit both the care recipient and caregiver.

Similar to existing research (Schaffler et al. 2019), caregivers in the current study described acting as information gatekeepers – bridging and interpreting information exchanged between the care recipient and health providers. In these instances,

there is the risk that cancer information is not accurately interpreted or comprehensively shared. Caregiver interpreters were likely to filter information about the diagnosis and prognosis from the care recipient, with reasons including facilitating a positive outlook and maintaining hope in care recipients, as well as avoiding their own emotional distress. The necessity for such information “editing” can be questioned; recent research suggest that disclosure of poor prognosis does not negatively impact psychological outcomes in Chinese people diagnosed with cancer; rather disclosure of poor prognosis information and promotion of positive communication between caregivers and care recipients was recommended (Nie et al. 2016).

Compromised communication about cancer-related information between caregiver and patient has been associated with discordance between caregiver and care recipient preferences for end-of-life care, which may negatively impact patient autonomy and accuracy in adhering to patient preferences for care (Shin et al. 2015). Inaccurate adherence to patient preferences for care is likely exacerbated in instances where key prognosis or treatment information is withheld from the patient due to language barriers. The findings underscore the importance of ensuring professional interpreters are available to broker information between providers and the person with cancer. The use of an untrained caregiver for the important role of brokering information between providers and people with cancer, and the impact on the patient and caregiver health outcomes, requires further research.

Participants were generally satisfied with communication with health providers, however, a key finding related to providers’ directness when sharing information. Research with CALD communities shows that Western communication about chronic disease can be considered too blunt, and that the direct communication of diagnosis and prognosis is experienced as confronting (Bosma et al. 2010; Kirby et al. 2018). Future research should further explore issues around cultural safety in discussions about cancer and how safety might inform health communication. Participants described some provider interactions as lacking empathy, which resulted in care recipients and caregivers feeling hopeless. Participants felt supported when care was personalized, provided with patience, and where participants could involve health providers that spoke their first language. The findings support the need for providers to be aware of cultural sensitivities related to disclosure of a cancer diagnosis, and that family consultation and involvement are paramount when discussing a cancer diagnosis. Improving communication skills to ensure health providers is confident to have nuanced discussions about cancer and its prognosis and understand that cultural sensitivities around cancer diagnosis and discussions of morbidity and mortality could foster improved outcomes in both care recipients and caregivers. The findings also suggest that access to health providers (e.g., GPs or specialists) who speak the first language of the patient and carer, and can explain the diagnosis, treatment, and prognosis in detail, may address CALD caregiver information support needs.

Our findings highlight the need for culturally tailored outreach programs to support Arabic- and Chinese-speaking caregivers of people with cancer that can be embedded within health-care services. A tailored telephone supportive care program for people affected by cancer from CALD communities has been trialed and considered acceptable by patients and caregivers in providing in-language, cancer-related, information and support (Shaw et al. 2013a). Our findings suggest the need for increased availability and ease of access to such programs designed to provide information and supportive care for caregivers from CALD backgrounds.

Such programs have the potential to improve the health outcomes of both caregivers and care recipients from CALD communities.

Study limitations

The qualitative design of the study is a strength; it enabled in-depth exploration of CALD cancer caregiver experiences residing in Australia. However, findings cannot be considered generalizable to all cancer caregivers from CALD communities. Furthermore, the study may have been limited by the differences in language and background between the interviewer and participants. The interviewer was a white woman from an Anglo-Saxon background who only spoke English. Although participants were able to speak English, it is possible that aspects of the interview were literally “lost in translation.” Interviews conducted in participants’ first language may have captured more nuance. Furthermore, it is not known if participants felt wholly comfortable sharing their stories with an outsider. Indeed, results showed that participants were more comfortable seeking *support* from a person with a similar background and language, and it is possible that a similar principal applies in the research setting.

Clinical and research implications

Caregivers from CALD communities experience a range of language, communication, and cultural barriers when seeking and finding information which can negatively impact their capacity to provide optimal care for their care recipient. Ensuring caregivers and care recipient from CALD communities are offered formal interpreter services even when they appear proficient in English is recommended. Facilitating access to formal interpreters at short notice is also important. Further research is needed to identify strategies to effectively communicate cancer-related information in a culturally sensitive manner to people affected by cancer from diverse backgrounds. Research to explore the experiences of cancer caregivers who do not speak English is also recommended because their challenges will likely be magnified by the language barrier.

Conclusion

Caregivers identified significant language and communication barriers that impacted their capacity to understand cancer-related information when providing care. Findings highlighted the importance of health providers offering and ensuring interpreter services are available for those from CALD communities, even when caregivers and patients may seem proficient in English, to ensure optimal understanding of cancer-related information. Our findings suggest that cultural differences in responses to a cancer diagnosis and discussions of treatment should inform health provider communication with both CALD caregivers and patients. Education of health providers about both cultural safety and sensitivity is a critical first step. In addition, culturally tailored outreach programs, designed to provide key cancer-related information, which are accessible to CALD caregivers have the potential to improve the health outcomes of both caregivers and their care recipients.

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Megan Hale: investigation; funding acquisition; data curation; data analysis; project administration; writing – original draft; writing – review & editing.

Carlene Wilson: conceptualization; investigation; methodology; data analysis; writing – original draft; writing – review & editing.

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References

- Alananzeh IM, Kwok C, Ramjan L, *et al.* (2019) Information needs of Arab cancer survivors and caregivers: A mixed methods study. *Collegian* **26**(1), 40–48. doi:10.1016/j.colegn.2018.03.001
- Australian Bureau of Statistics (2021a) Australia's population by country of birth. <https://www.abs.gov.au/statistics/people/population/australias-population-country-birth/latest-release#related-abs-publications> (accessed 12 July 2023).
- Australian Bureau of Statistics (2021b) Cultural diversity: Census. Canberra ACT: ABS. <https://www.abs.gov.au/statistics/people/people-and-communities/cultural-diversity-census/2021> (accessed 12 July 2023).
- Australian Institute of Health and Welfare (2019) Cancer in Australia 2021. Cancer series no. 133. Cat. no. CAN 144. Canberra: AIHW.
- Berger R (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research* **15**(2), 219–234. doi:10.1177/1468794112468475
- Bosma H, Apland L and Kazanjian A (2010) Cultural conceptualizations of hospice palliative care: More similarities than differences. *Palliative Medicine* **24**(5), 510–522. doi:10.1177/0269216309351380
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**(2), 77–101. doi:10.1191/1478088706qp063oa
- Butow PN, Bell ML, Aldridge L, *et al.* (2013) Unmet needs in immigrant cancer survivors: A cross-sectional population-based study. *Supportive Care in Cancer* **21**, 2509–2520. doi:10.1007/s00520-013-1819-2
- Høeg BL, Frederiksen MH, Andersen EAW, *et al.* (2021) Is the health literacy of informal caregivers associated with the psychological outcomes of breast cancer survivors? *Journal of Cancer Survivorship* **15**, 729–737. doi:10.1007/s11764-020-00964-x
- Janda M, Steginga S, Dunn J, *et al.* (2008) Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Education and Counseling* **71**(2), 251–258. doi:10.1016/j.pec.2008.01.020
- Kent EE, Rowland JH, Northouse L, *et al.* (2016) Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer* **122**(13), 1987–1995. doi:10.1002/cncr.29939
- Kinnane NA and Milne DJ (2010) The role of the Internet in supporting and informing carers of people with cancer: A literature review. *Supportive Care in Cancer* **18**(9), 1123–1136. doi:10.1007/s00520-010-0863-4
- Kirby E, Lwin Z, Kenny K, *et al.* (2018) “It doesn't exist...”: Negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliative Care* **17**(1), 1–10. doi:10.1186/s12904-018-0343-z
- Lambert S, Loban E, Li J, *et al.* (2021) Chronic illness management in culturally and linguistically diverse patients: Exploring the needs, access, and understanding of information. *Qualitative Health Research* **31**(13), 2426–2439. doi:10.1177/10497323211040769
- Lim BT, Butow P, Mills J, *et al.* (2019) Challenges and perceived unmet needs of Chinese migrants affected by cancer: Focus group findings. *Journal of Psychosocial Oncology* **37**(3), 383–397. doi:10.1080/07347332.2018.1551261
- Møller -JJK, Jespersen E, Lindahl-Jacobsen R, *et al.* (2020) Associations between perceived information needs and anxiety/depressive symptoms among cancer caregivers: A cross-sectional study. *Journal of Psychosocial Oncology* **38**(2), 171–187. doi:10.1080/07347332.2019.1664699
- Morris SM and Thomas C (2001) The carer's place in the cancer situation: Where does the carer stand in the medical setting? *European Journal of Cancer Care* **10**(2), 87–95. doi:10.1046/j.1365-2354.2001.00249.x
- Nie X, Ye D, Wang Q, *et al.* (2016) Poor-prognosis disclosure preference in cancer patient–caregiver dyads and its association with their quality of life and perceived stress: A cross-sectional survey in mainland China. *Psychooncology* **25**(9), 1099–1105. doi:10.1002/pon.4055
- O'Callaghan C, Schofield P, Butow P, *et al.* (2016) “I might not have cancer if you didn't mention it”: A qualitative study on information needed by culturally diverse cancer survivors. *Supportive Care in Cancer* **24**, 409–418. doi:10.1007/s00520-015-2811-9
- Schaffler JL, Tremblay S, Laizner AM, *et al.* (2019) Developing education materials for caregivers of culturally and linguistically diverse patients: Insights from a qualitative analysis of caregivers' needs, access and understanding of information. *Health Expectations* **22**(3), 444–456. doi:10.1111/hex.12867
- Shaw J, Butow P, Sze M, *et al.* (2013a) Reducing disparity in outcomes for immigrants with cancer: A qualitative assessment of the feasibility and acceptability of a culturally targeted telephone-based supportive care intervention. *Supportive Care in Cancer* **21**, 2297–2301. doi:10.1007/s00520-013-1786-7
- Shaw J, Harrison J, Young J, *et al.* (2013b) Coping with newly diagnosed upper gastrointestinal cancer: A longitudinal qualitative study of family caregivers' role perception and supportive care needs. *Supportive Care in Cancer* **21**(3), 749–756. doi:10.1007/s00520-012-1575-8
- Shaw JM, Shepherd HL, Durcinoska I, *et al.* (2016) It's all good on the surface: Care coordination experiences of migrant cancer patients in Australia. *Supportive Care in Cancer* **24**, 2403–2410. doi:10.1007/s00520-015-3043-8
- Shin DW, Cho J, Kim SY, *et al.* (2015) Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psychooncology* **24**(2), 212–219. doi:10.1002/pon.3631
- Sklenarova H, Krümpelmann A, Haun MW, *et al.* (2015) When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* **121**(9), 1513–1519. doi:10.1002/cncr.29223
- Sung H, Ferlay J, Siegel RL, *et al.* (2021) Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians* **71**(3), 209–249. doi:10.3322/caac.21660
- Sun V, Puts M, Haase K, *et al.* (2021) The role of family caregivers in the care of older adults with cancer. *Seminars in Oncology Nursing* **37**(6), 151232. doi:10.1016/j.soncn.2021.151232
- Wang T, Molassiotis A, Chung BPM, *et al.* (2018) Unmet care needs of advanced cancer patients and their informal caregivers: A systematic review. *BMC Palliative Care* **17**(1), 1–29. doi:10.1186/s12904-018-0346-9
- Wiley G, Piper A, Butow AP, *et al.* (2018) Developing written information for cancer survivors from culturally and linguistically diverse backgrounds: Lessons learnt. *Asia-Pacific Journal of Oncology Nursing* **5**(1), 121–126. doi:10.4103/apjon.apjon_63_17