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“Thrown in the deep end” - Health System Experiences of Cancer Carers from Priority Populations: a qualitative study

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Abstract

Background

Informal cancer carers report high unmet needs. However, few studies have examined experiences and support needs among carers from priority population groups, including those from culturally and linguistically diverse (CALD) communities, rural/remote areas, and carers from lesbian, gay, bisexual, transexual, intersex, queer, asexual plus (LGBTIQA+) communities.

Aims

This study aimed to explore supportive care and health service experiences of informal cancer carers from priority population groups in Australia.

Methods

Online focus groups were conducted by specialist agencies with experience working with people from priority populations. Semi structured focus groups explored carer experiences with health providers and services, access to supports and resources, and recommendations for system improvement. Sessions were digitally recorded, transcribed, and analysed using thematic analysis.

Results

Eight focus groups were conducted with a total of 41 carers (n = 17 rural/remote; n = 8 LGBTIQA+, n = 16 CALD). Most carers were women (n = 28;68%), with the most common age group was 18–39 years (n = 16;39%). While some positive experiences were reported, many carers highlighted challenges and areas for health system improvement. Main themes included isolation in the care role, absence of information provision, limited coordination of services, inadequate communication with health providers, and lack of recognition of carers as part of the care team.

Conclusions

Despite longstanding calls to recognise family carers as integral members of the care team, this remains limited in practice. Establishing pathways to connect carers with appropriate and tailored support is a priority. Future research should evaluate models that embed carer support into routine cancer care to improve outcomes.

Background

There has been a significant shift toward outpatient and home-based cancer care(1, 2). In turn, the reliance on informal carers, namely partners, adult children, close family and friends, to provide practical, emotional and medical support to patients has increased(3). While caring for someone with cancer can be rewarding, it often imposes a substantial burden, including financial strain, reduced quality of life, and

psychological distress(4–6). This burden may be further compounded as carers navigate unfamiliar health systems.

Healthcare systems, especially in the context of cancer, are inherently complex, and certain population groups face additional challenges when interacting with them. For example, people who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual and/or other (LGBTQIA+) often hesitate to disclose their sexual orientation or gender identity due to fears of discrimination and negative clinician attitudes, which can limit access to tailored information and support(7, 8). Similarly, individuals from culturally and linguistically diverse (CALD) backgrounds frequently report feeling disrespected or misunderstood because of cultural beliefs and practices(9, 10). They may also face communication challenges linked to limited English proficiency, low health literacy, and insufficient interpreter services(11–13). Inadequate health system supports have also been reported by people residing in rural and remote areas(14, 15) due to the geographical distance from treatment centres, limited availability of services, and delays to diagnosis and treatment(16–18).

Despite the growing recognition of carers' critical role in cancer care(1), research exploring how carers from priority populations, such as LGBTIQA+, CALD, and rural and remote carers, experience and navigate health systems remains limited. Addressing this gap is essential to inform equitable health service design and targeted support strategies that meet the diverse needs of carers across the cancer trajectory.

The present study aimed to explore health system experiences and support needs among carers of people with cancer from priority population groups in Australia.

Methods

This qualitative study formed part of a larger project examining the unmet needs of cancer carers that included a cross-sectional online survey of Australian cancer carers (19). A qualitative phase, reported here, comprised a series of facilitated focus group discussions to explore experiences within the health system for members of select priority populations. Two agencies were engaged by the research team to facilitate the focus groups one specialising in research and community development with CALD communities in Australia (the LOTE Agency), with the other (MMR) experienced in qualitative health research, including working with priority populations and conducting cancer-related studies. The LOTE Agency facilitated groups with members of the CALD communities with MMR facilitating focus groups with participants from rural/remote areas and LGBTIQA+ communities.

Recruitment Summary

Two recruitment strategies were employed.

Strategy a) The primary recruitment approach involved the research team emailing a study invitation to participants of the online survey who had consented to be contacted regarding further research opportunities and who self-identified as CALD or LGBTIQA+ or were classified as residing in a rural/remote area[1].

Strategy b) once the national survey participant list was exhausted, the two agencies engaged to facilitate the focus group discussions utilised their independent databases to identify additional eligible participants and send invitations.

Eligibility

Eligible participants met the following criteria: aged 18+ years; have cared for or provided support to someone with cancer within the past five years; the person with cancer was aged 15+ years when they were diagnosed, currently residing in Australia; and identified as a) residing in a rural or remote location, b) a member of the LGBTIQA+ community, or c) spoke Cantonese, Mandarin, Vietnamese, Arabic or Punjabi language at home.

Participant Screening and Consent

Participant invitations contained a brief description of the study and a link to an online Qualtrics survey form. The form commenced with a study welcome page detailing the study aims and eligibility criteria, and a link to view/download the Patient Information and Consent Form (PICF). Interested individuals completed a pre-screening survey to determine eligibility. Eligible consenting prospective participants were contacted by phone to confirm their interest and availability and scheduled into appropriate focus group sessions. Participants received a $100 e-voucher the day after their session as a token of appreciation for their contribution.

Discussion Guide

Discussion guides were developed in consultation with the research team, LOTE and MMR. Focus group sessions were conducted online by trained facilitators from each agency using the secure Zoom video conferencing platform.

Data Collection

Each group discussion ran for approximately 90 minutes. Focus group sessions were digitally recorded with participants' consent. Focus groups were conducted between November 2024 to February 2025. For focus group sessions with CALD participants, an independent NAATI-certified (National Accreditation Authority for Translators and Interpreters) interpreter was also present.

Analysis and Reporting

All focus group recordings were transcribed verbatim, and de-identified to ensure confidentiality. Data were analysed thematically following the six steps outlined by Braun and Clarke(20). For the data relating to LGBTIQA+ and rural/remote participants, two investigators [BM, MM] independently reviewed transcripts and categorised data into themes and sub-themes. Then, using an iterative process, themes and codes were compared and re-worked, with a third researcher consulted for consensus where required.

For data from CALD participants, thematic analysis was conducted using NVivo 14(21) by independent investigator [EY], Themes and sub-themes were discussed amongst the research team [SC and VW] to ensure consistency and rigour. Discrepancies in coding were resolved through discussion and consensus [EY, SC and VW].

Ethical Approval

This study was conducted in accordance with the Declaration of Helsinki. Ethics approval was obtained from the Human Research Ethics Committees Deakin University (HEAG-H 34-2024).

[1] Residential postcode used to define regionality using the Modified Monash (MM) Model 2023 edition (22). With rural/remote reflecting residential postcodes MM3-MM7.

Results

Eight focus groups were conducted with a total of 41 participants, comprising three groups with rural/remote carers (42%, n=17), two groups with LGBTIQA+ carers (20%, n=8), and three groups with CALD carers (39%, n=16). Most participants were female (68%, n=28), and the most common age bracket was 18-39 years (39%, n=16) (Table 1).

Table 1: Participant characteristics (n=41)

		n	%
Priority Population	Rural/remote residing	17	41.5
	LGBTQIA+	8	19.5
	CALD	16	39.0
	Chinese (Mandarin and Cantonese speaking)	8	19.5
	Vietnamese	3	7.3
	Arabic speakers	2	4.9
	Punjabi speakers	3	7.3
Gender Identity	Female	28	68.3
	Male	10	24.4
	Non-binary	3	7.3
Care status	Current Carer	15	36.6
	Past carer (within last 5 years)	26	63.4
Carer age	18-39 years	16	39.0
	40-59 years	10	24.4
	60 years and over	15	36.6

Findings

Four key themes were identified, each comprising of three to five sub-themes. Most themes were consistent across all priority groups, with differences noted where they emerged. Theme Three was specific to LGBTIQA+ and CALD carer. Supporting quotations for each theme are provided in Tables 2 to 5.

Theme One: Isolation in the care role

a) Overlooked and not recognised

Participants consistently reported that their needs as carers were overlooked within the health system. Many noted that “no one ever asked” about their wellbeing. This lack of attention was attributed to a primary focus on the patient and cancer treatment, alongside limited awareness of carers’ roles and needs, and perceptions that carers fell outside the scope of clinical responsibility.

b) Limited access to information

Participants described insufficient and inconsistent information from health providers, particularly regarding symptom management, medications, and expectations of the caring role. Providers were often not forthcoming with information, requiring carers to ask questions, despite uncertainty about what to ask or who to approach. Information was frequently communicated only to the patient, who often struggled to recall details later, leaving carers ill-equipped to provide care at home. The lack of accessible, carer-inclusive communication contributed to frustration, anxiety, and a sense of being "thrown in the deep end," especially at the point of diagnosis when carers were also navigating a complex and unfamiliar health system.

c) Lack of guidance

Participants reported minimal guidance in navigating services and a lack of proactive referral to resources, information, or carer-specific supports. As a result, many perceived that few services were available or appropriately tailored to their needs. Where supports did exist, they were often introduced too late, commonly during palliative care, or following the care recipient's death. For some, this delayed or absent support, along with the withdrawal of services following bereavement, intensified feelings of isolation by underscoring unmet needs throughout the caring journey.

d) Perceived scarcity of support services

Few participants reported accessing formal support services, largely due to limited awareness and a lack of referral. Among those who did engage with services, particularly LGBTIQA+ and rural/remote participants, hospital-based supports such as cancer care nurses or patient navigators were most commonly used, with these services valued for helping coordinate care and facilitate interactions with the health system.

Awareness of carer-specific supports, including those offered by cancer advocacy or carer organisations, was generally low. Where participants had engaged with these services, experiences were mixed. Some perceived that available resources were primarily oriented toward patient needs rather than those of carers, while others reported that services did not meet their information needs. This contributed to a broader perception that tailored support for carers was limited or unavailable, reinforcing feelings of isolation and frustration.

Table 2. Illustrative quotes for Theme One: Isolation in the care role

Sub-theme	Participant quotes
a) Overlooked and not recognised	*"No-one is asking you. No-one even cares that you are a carer"* (LGBTIQA+ carer). *"It feels like with doctors and specialists that they focus on the illness, not the actual person…… That's why the carers are getting forgotten."* (LGBTIQA+ carer).
b) Limited access to information	"*You get told nothing, honestly. You have to find all that yourself. You have to do that research yourself. I find if you don't ask the question, nobody's offering you the answer."* (Rural/remote carer). "*I think more communication from healthcare providers would be great. It would help reduce anxiety because at the start, I didn't know what to expect."* (Chinese carer).
c) Lack of guidance	*"Your doctor is supposed to do a lot of referrals to this and that. But we never had any referrals from any of the doctors. Social worker, allied health, or anything else, it never happened."* (Rural/remote carer). *"I can't say that there was a lot of individual support for me while she was alive, but after she passed away there was counselling available. It's while it's all happening and while you're doing the caring that there is a lack of offers of support, or places that are appropriate for support."* (LGBTIQA+ carer).
d) Perceived scarcity of support services	*"…They didn't tell me what was on offer…I never heard from them again…that was really disappointing and very frustrating because when you have an experience like that then you feel like there's just no support network out there that you can turn to…you just feel alone. You have to look at everything yourself online and figure it out all yourself."* (Arabic/South Asian carer).

Theme Two: Recognised and valued as part of the Care Team

Participants emphasised the importance of being recognised, included, and supported as legitimate members of the care team. A lack of recognition contributed to feelings of invisibility, exclusion, and unmet needs.

a) Inclusion in the care team and decision-making

Feeling recognised as part of the care team was central to carers' experiences. Positive experiences were characterised by providers who actively included carers in discussions, acknowledged their role, and considered their perspectives in decision-making. This fostered a sense of being an "integral part of the process." In contrast, lack of acknowledgment from specialists, general practitioners, and nurses led

to feelings of being “invisible,” dismissed, and undervalued. These experiences were often described as demeaning or condescending, contributing to a sense of exclusion from care.

b) Barriers to legitimacy for non-family carers

Non-family carers described additional challenges in being recognised as legitimate participants in care. These included uncertainty about their rights to access information, ask questions, or engage with services. Some felt that providers did not view them as part of the care team and perceived them as “interfering” or overstepping boundaries. These barriers further limited their ability to support care recipients effectively.

c) Structural and contextual barriers to inclusion

For rural and remote carers, structural factors compounded experiences of exclusion. The need to travel long distances to metropolitan centres introduced logistical, financial, and emotional burdens, including navigating unfamiliar environments, time away from work, and accommodation costs. These challenges were intensified by a lack of tailored information, particularly around care transitions, such as discharge and transporting patient’s home. These cumulative pressures contributed to greater strain and reinforced feelings of isolation from the health system.

d) Respectful, inclusive, and culturally responsive care

The quality of provider interactions shaped whether carers felt recognised and included. Respectful, compassionate, and clear communication fostered trust and a sense of belonging. For LGBTIQA+ participants, inclusive practices enhanced feelings of acceptance, while CALD participants valued culturally responsive care. Access to same-language providers, in particular, improved communication, reduced reliance on interpreters, and enabled more culturally nuanced understanding. Conversely, negative interactions—such as feeling dismissed, rushed, or labelled “difficult”—discouraged engagement and reinforced exclusion.

Table 4. Illustrative quotes for Theme Three: Recognition and belonging within the Care Team

Sub-theme	Participant quotes
a) Inclusion in the care team and decision-making	*"…I was seen as very much part of the team caring for him." (Regional, F, Friend, P).*
	"I definitely did not feel seen. I kind of felt really excluded… I felt like I was looked past when things were being discussed. Like nothing was ever said to both of us. It felt kind of really uncomfortable, like I wasn't there". (LGBTIQA+ carer).
b) Barriers to legitimacy for non-family carers	*"Caring for my friend, it's almost like 'Why are you interfering? What's it to do with you?' As though I'm not part of this, and therefore I have no right of access to any of the information that I'm trying to seek."* (Rural/remote carer).
c) Structural and contextual barriers to inclusion	*"I've got to get a motel or an Airbnb, and I stay there for a couple of days. I had to go down by myself. So, you find yourself very isolated…you get a bit distressed."* (Rural/remote carer).
	"He had surgery in [regional centre], which is 280ks from here. ……It's really quite scary if you are not medically qualified to have to drive five hours to get home with someone who's not very well in the car with you. I felt abandoned. That is the feeling you get, complete abandonment……" (Rural/remote carer).
d) Respectful, inclusive, and culturally responsive care	"*Mum…has a very specific concept of health and well-being. So, trying to message what the Western concept of illness and wellbeing is and trying to marry that up with mum's concept of it, which is much more Chinese and Asian… there's probably an added pressure…." (Vietnamese carer).*
	"…we needed to have a female speaking doctor, but we didn't find any. So that would have helped even more because we were seeing a gynecologist. [But], we had to go to the male one. And it's a bit cultural as well." (Arabic / South Asian carer)

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Theme Three: Feeling Misunderstood – Navigating Cultural- and Identity-based Barriers

a) Misrecognition and exclusion

Some LGBTQIA+ described experiences of being misunderstood or excluded within healthcare and support settings. Misrecognition of relationships was evident, with some same-sex partners incorrectly identified (e.g., as a parent rather than a partner), particularly when there was an age difference. Others noted a lack of tailoring of information to their relationship context, such as receiving heteronormative or gender-incongruent materials.

Feelings of exclusion also extended to support services. One participant described isolation when attending a carer support group where all other attendees were heterosexual partners. For some,

anticipated or experienced discrimination acted as a barrier to seeking formal support, limiting engagement with services and reinforcing isolation.

b) Language barriers and the burden of interpretation

CALD carers described significant challenges related to language, particularly when informal interpretation was required. Participants often assumed responsibility for interpreting complex medical information during consultations, which created pressure to convey accurate information and heightened their sense of responsibility in supporting care recipients and informing family decision-making.

Language barriers were compounded by the absence of equivalent terms for some medical concepts, making accurate interpretation difficult. These challenges increased stress and contributed to uncertainty in understanding and communicating critical health information.

c) Navigating cultural beliefs and expectations in care

Carers from CALD backgrounds also described the complexity of navigating cultural beliefs alongside Western medical approaches. This included balancing cultural understandings of illness with the need to communicate and support engagement with biomedical care. Decision-making was sometimes influenced by prior experiences or perceptions of healthcare systems in countries of origin.

Cultural norms also shaped communication and care preferences, including sensitivities around discussing end-of-life care. Some participants noted that such discussions were considered inappropriate or “disrespectful” within their cultural context, and preferred providers to initiate these conversations. Preferences for same-gender providers were also expressed as important for culturally appropriate care.

d) Cultural barriers to psychosocial support

Across CALD groups, engagement with mental health services was uncommon. Barriers included cultural norms emphasising stoicism and prioritising others’ needs, as well as perceptions that providers lacked understanding of culturally shaped health beliefs. Participants also expressed a preference for in-language support from individuals who understood their cultural context. These barriers limited access to psychosocial care and contributed to unmet support needs.

Table 3. Illustrative quotes Theme Two: Feeling Misunderstood – Navigating Cultural- and Identity-based Barriers

Sub-theme	Participant quotes
a) Misrecognition and exclusion	*"[I think] there are supports out there if you need them. Maybe if I were in a heterosexual relationship, I might have been more willing to follow those up. I think sometimes I'm a bit reluctant to pursue those kinds of things because I'm always thinking 'oh, what if they do have a problem with me being gay…?"* (LGBTIQA+ carer).
b) Language barriers and the burden of interpretation	*"Jargons. The medical terminology…Anything to do with cancer…. [it's] a bit hard for people to understand. In Arabic, we speak very casually. So when it comes to medical jargon it was just hard… And because the dialects are also different, trying to explain it properly without freaking them out or making us understand."* (Arabic / South Asian carer)
c) Navigating cultural beliefs and expectations in care	"*The thing about not accessing mainstream services for me is that I sometimes feel like even if I call them up, they're not going to understand what the hell I'm talking about. You know, when I start talking about mum and her weird ideas of health and you know they're not weird. They're just different conceptions of health…. then I have to start right at the beginning about what Asian culture is like, and how we see health and well-being. And then it takes forever…".* (Vietnamese carer). *"…With some cultures, it's a bit unconventional to discuss things like end-of-life care or end of life options…".* (Arabic / South Asian carer)
d) Cultural barriers to psychosocial support	*"To be proactive on our part to kind of go out and seek [mental health support]… I think [in] Vietnamese culture, we just say, 'no, we're going to be stoic, we're just going to get through this'…also [there is] other pressure about filial duty that compels us to not think of ourselves first."* (Vietnamese carer).

Theme Four: Carer-Informed Recommendations for System Improvement

Participants across all groups proposed a range of recommendations to improve how health systems recognise and support carers. These recommendations reflected the unmet needs identified throughout their experiences and emphasised the importance of structured, inclusive, and accessible supports.

a) Recognition and inclusion of carers in the care team

Participants emphasised the need for formal recognition of carers as integral members of the healthcare team. Suggested strategies included embedding carer recognition within health system policies and practices and ensuring healthcare providers actively include carers in discussions about treatment and care. Participants also highlighted the importance of assessing carer needs and equipping carers with practical information and training, such as medication management, post-treatment care, and expectations across the care trajectory.

b) Improving access to information and navigation support

Participants recommended more accessible and coordinated approaches to information and service navigation. This included the development of centralised platforms where carers can easily access information about available supports, and the proactive provision of information by healthcare services. The introduction of dedicated navigation roles or single points of contact was also proposed to assist carers in understanding the system and accessing services across different stages of care. For CALD communities, participants stressed the importance of translated materials and targeted promotion of services.

c) Strengthening psychosocial and peer support for carers

Enhanced emotional and psychological support was identified as a priority. Participants highlighted the value of peer support programs that enable connection with others who share similar experiences, particularly when tailored to specific populations (e.g., cultural, language, gender, or sexual identity groups). There was also a need for culturally appropriate mental health services that address stigma and are responsive to diverse beliefs and preferences.

d) Expanding and adapting financial support systems

Participants identified financial strain as a significant burden and recommended expanded, more flexible financial supports. Suggestions included increasing financial assistance for carers who take unpaid leave, extending eligibility criteria to reflect shared caregiving arrangements, and introducing more responsive systems based on caregiving intensity. Additional support for travel-related costs—such as fuel, transport, and accommodation—was also highlighted as essential, especially for rural and remote carers.

e) Enhancing accessibility and equity of healthcare services

Improving the accessibility and responsiveness of healthcare services was a key priority, particularly for carers from CALD and rural/remote communities. Recommendations included expanding access to interpreter services, improving coordination of appointments to account for travel burden, and ensuring culturally sensitive care practices (e.g., gender-matching providers where appropriate). These changes were seen as critical to enabling equitable access and reducing systemic barriers.

Table 5. Illustrative quotes Theme Four: Carer-Informed Recommendations for System Improvement

Sub-theme	Participant quotes
a) Recognition and inclusion of carers in the care team	*"Carers need to be heard and acknowledged, instead of being taken for granted, or just like a shadow of the patient."* (LGBTQIA+ carer). *"The other thing about carers being involved right from the beginning is that it would make a lot of carers realise that it is ok for them to be part of this whole journey, that it is ok for them to ask questions. It would give you more authenticity in terms of being there and saying 'well, I'm part of this'."* (LGBTQIA+, carer).
b) Improving access to information and navigation support	*"They really need to embed it into all levels of the organisation. So, when you speak to a nurse or a clinician, they all have knowledge of how to get through to the carer. So, they're all skilled. Because it can't always be 'oh, the care support workers are on from 9 to 3, and you're there at 7pm. It kind of needs to be embedded. So 'carers' isn't this island over there."* (Rural/remote carer). *"I would have liked to be able to sit down with [someone] who could say 'these are the services that we offer, this is how you use those services or get in touch with them. Can we make an appointment to sit down with you and run through them?' That would have just saved so much heartache, so much worry, and so much time. And a lot of anger."* (Rural/remote carer).
c) Strengthening psychosocial and peer support for carers	*"Mental health support is important. Why are they not talking about cancer carers? 'Your health is important, you need help as well at all the stages, from the start to the end'. Why isn't there any resources out there, for different people in easy wording. Not in difficult working or medical terms."* (LGBTQIA+ carer). *"Hearing other people's experiences is really useful. It's really complicated and there's a whole lot of aspects to it, and yeah, it's helpful to hear other people's experiences. I can see I'm not on my own here."* (Regional, F, Friend, P) *"To talk to people who understand. Who know Asian culture. To make it acceptable."* (South Asian carer). *"Definitely separate group for different segments because you can relate to them, you can relate to their stories, you won't feel isolated, you won't be shocked."* (LGBTQIA+ carer).
d) Expanding and adapting financial support systems	*"If there was just a little bit of financial support to give me, you know 3 or 4 days, 5 days, to take leave without pay. That would have just helped so much."* (Rural/remote carer). *"I'm probably looking at the more functional side of things, like transport to appointments, like navigating city and parking, and having a disabled person,*

	getting them into a building. I'm kind of so caught up with the functional side of it." (Rural/remote carer).
	"…They might offer specific benefits for cancer carers to relieve stress in daily life. This could include financial support or programs similar to employee assistance programs" (Chinese carer)
e) Enhancing accessibility and equity of healthcare services	*"Maybe there needs to be a little bit more training, education for people in the medical fraternity about the effects that a very serious health issue can have on the carers. And how to talk to us [LGBTQIA+], I can't imagine there are many oncologists out there that had a subject on 'caring for the carer'."* (LGBTQIA+ carer).
	"I don't access mainstream services. I feel like even if I call them up, they're not going to understand what the hell I'm talking about. If people knew about that [cultures] it would help." (Chinese carer).

Discussion

The current study provides important insights into the experiences of cancer carers across diverse priority populations, highlighting both common systemic challenges and unique barriers shaped by social, cultural, and geographic contexts.

Consistent with existing literature, carers in this study reported feeling isolated in their care role with substantial unmet informational and support needs, particularly in relation to navigating complex health systems and understanding their role in care provision(22, 23). The finding that carers frequently needed to seek out information independently reflects well-documented gaps in carer-focused communication(24). While independent information seeking among carers can involve engaging with health professionals, carers are increasingly relying on internet searching(23, 25). Online resources may provide an accessible pathway to information; however, the quality of such information is not assured, with studies indicating that carers often express concerns about its reliability(26). Additionally, this places barriers on carers with low e-health literacy or with specific language needs.

Additionally, there was limited awareness and use of formal support services, cited largely due to inadequate referral pathways and lack of proactive engagement from healthcare providers. This finding is consistent with research indicating that carer support services are frequently underutilised, not because of lack of need, but due to poor visibility and accessibility within the healthcare system(27, 28). However, structural barriers to support, such as service availability wait times, geographical location and availability of translators, further inhibit access(11, 14, 29). Moreover, participants in this study reported that supports were often introduced too late in the caregiving trajectory(27, 30), limiting effectiveness and contributing to poorer outcomes(31).

Feeling misunderstood by healthcare providers and health systems was commonly reported by carers who identified as LGBTIQA+ or from a CALD background. LGBTIQA+ carers described experiences of exclusion and heteronormative assumptions within healthcare settings, highlighting systemic gaps in cultural competence and inclusive service provision(7, 32). CALD carers in this study faced additional challenges related to language barriers, health literacy, and navigating cultural differences in healthcare decision-making. These findings are consistent with literature demonstrating that Western healthcare models often fail to provide culturally safe care(33, 34). Collectively, these findings highlight systemic cultural and identity-based barriers to care.

While some participants expressed some positive experiences with healthcare providers, a central finding was a lack of recognition and integration of carers within the healthcare team, reflecting prior studies reporting that carers and patients encountered poor communication and limited guidance from health professionals(35). Participants described feeling “invisible” or excluded from clinical discussions, despite playing a critical role in supporting care recipients. This was particularly evident for non-family carers. Additionally, rural and remote carers reported a lack of recognition for the additional burdens associated with their care; with travel, cost, and dislocation from local support networks prominent. Findings highlight that carer needs are often secondary and reinforce known geographic inequities in access to centralised cancer services(6, 14, 15, 29, 36). Collectively, these findings align with prior research demonstrating that carers are often marginalised within patient-centred care models, which prioritise the individual patient while overlooking the broader care network(37). Studies have suggested clinician communication training(38), and support programs to prepare carers to provide clinical care while building capacity to manage their stressors and emotions as a key priority(39), with evidence suggesting that meaningful inclusion of carers in decision-making processes can improve both patient and carer outcomes(40). However, the present study highlights an ongoing disconnect between policy recommendations and routine clinical practice.

Implications (clinical and research)

Study findings reflect the urgent need for health systems to formally recognise and integrate carers as part of the care team. Carers recommended improvements centred on inclusion, proactive communication, and coordinated access to supportive services such as patient navigation programs, routine carer assessment, and culturally tailored psychosocial and financial support services. Achieving these identified needs requires a systems-level approach through clear, dedicated pathways and highlights the importance of tailored interventions that acknowledge the diverse experiences and complex challenges faced by carers, particularly for those who belong to one or more priority population.

Limitations

The present study reflected experiences limited to Australian-based carers, so not reflective of views of carers in other settings. The voluntary nature of participation has the potential for self-selection bias, as those with stronger opinions or greater challenges may have been more likely to participate.

Conclusions and implications

The current study provides important insights into the supportive care needs and health system experiences of informal cancer carers from three priority populations in Australia, those identifying as LGBTIQA+, those living in rural and remote areas, and those from culturally and linguistically diverse (CALD) communities. The findings highlight the need for health systems to formally recognise carers as integral members of the care team and to implement structured, inclusive approaches that address their informational, emotional, and practical needs. Support services must be culturally appropriate and inclusive of gender and sexual diversity, while also accounting for the unique circumstances faced by carers, such as geographic isolation and travel burden. Improving carer support requires a coordinated, systems-level response that embeds routine information provision, proactive communication, and timely referrals into standard cancer care pathways, with a strong focus on equity and inclusivity. Future research should test scalable models to sustainably integrate carer support into policy and clinical practice, with the goal of improving outcomes for carers across the disease trajectory.

Declarations

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Conflict of Interest Statement

No relevant disclosures.

Data Availability Statement

The datasets generated and/or analysed during the current study are not publicly available due to the sensitive nature of the focus group discussions and the risk of participant identification. De-identified

excerpts may be available from the corresponding author on reasonable request, subject to ethics approval and participant consent.

Authorship Contribution Statement

SC, TL, VW and SC conceived and designed the study. SC, TL, VW, BM and MM developed the study materials and interview/focus group guide. BM and MM conducted the focus groups. BM, MM, EY, VW and SC performed data transcription and data management.

BM, MM, EY, VW and SC conducted data analysis, including coding and theme development. SC led interpretation of the findings with input from all authors.

SC, EY and VW drafted the manuscript. All authors critically revised the manuscript for important intellectual content, approved the final version, and agree to be accountable for all aspects of the work.

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