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Codesigning a supportive online resource for Australian cancer carers: a thematic analysis of informal carers' and healthcare professionals' perspectives about carers' responsibilities and content needs

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ABSTRACT

Objective To gather preliminary qualitative data that will assist in the codesign and development of a new informational and supportive website to assist informal cancer carers in Australia.

Design and setting Utilising a previously tested codesign process, informal carers' experiences and perspectives, including those of healthcare professionals', were examined via focus groups and/or interviews. Data were analysed via thematic analysis.

Participants Rural (n=9) and urban (n=11) carers', and healthcare professionals' (n=8) perspectives were collected. Carers participated in a focus group (n=9) or telephone interview (n=11). Healthcare professionals completed an interview (n=6) or online survey (n=2).

Results Rural and urban carers typically felt ill prepared for their multitudinal caregiving responsibilities. Supporting patient-to-healthcare professional liaisons could especially challenge. Carers' biopsychosocial and fiscal strains were affected by patients' hardships and available informal supports. Rural carers described greater social support than urban carers. Both rural and urban carers also described discontentment related to a carer neglecting healthcare system. Both carers and healthcare professionals endorsed the need for a user-friendly, carer-specific website encompassing practical information and resources, peer-driven advice and evidence-based illness information, tailored to the Australian context.

Conclusions Carers and healthcare professionals recognise the pressing need for an Australian, cancer carer-specific online resource. Findings will inform the next phase, where a resource will be designed, developed and tested.

BACKGROUND

Informal carers perform vital tasks for patients with cancer, including managing medications and symptoms, personal care, social and emotional support, and transportation

Strengths and limitations of this study

► Codesigned study involving qualitative focus groups and interviews with Australian carers that will contribute to the development of a new cancer carer website.

► Experiences and perspectives of informal carers from urban and rural locations pertaining to the development of a new website were included in this research.

► Perspectives of cancer-specific healthcare professionals pertaining to this website, based in rural and urban locations were assessed in collaboration with, and comparison to, the carers' needs and perspectives.

► The sample size pertaining to the qualitative data is relatively small, and further investigation is warranted to support the findings.

to appointments.[1] Most carers are inadequately informed about the illness and carer requirements and worry about the patient's prognosis.[2] Patient unmet needs are significantly related to the emotional health and well-being of the carer,[3] and the increasing preference to receive palliative and end-of-life care in the home.[4] Supportive services and resources designed specifically for informal cancer carers are needed, in order to assist their effective care and management of cancer-related financial, emotional and mental burdens.[5–7]

Although some interventions for cancer carers have demonstrated improved carer outcomes, whether carers find them acceptable beyond research settings remains unclear.[8] A systematic review of 33 studies[9]

found only 8% examined interventions informed by carer consultation, 46% assessed intervention acceptability for carers and none reported on transitioning interventions into non-clinical settings.

Internet-based resources are readily accessible, which are vital for cancer carers needing immediate information on symptomatic management. They are particularly relevant to those unable to travel lengthy distances to access health services, and has been shown in previous studies to be efficacious in reducing patient and carer isolation in Australian rural areas.[10] Around 95% of medical specialists reside in cities[11] while around 29% of Australians live in rural/remote areas, with disease burden being greater in these areas compared with metropolitan areas.[12] Additionally, the need for online resources was evident during the COVID-19 pandemic, where protective restrictions saw the replacement of in-person with remote care. Beneficial resources for cancer carers need to be designed specifically for them and need to contain evidence-based information.[13 14] In an assessment on suitability, readability, quality and usefulness of 55 cancer carer websites, none were considered 'optimal'; the majority were considered 'adequate'.[15] Most information focuses on carers' care provision while neglecting carers' own needs, despite research indicating that carers seek information about managing personal well-being.[16]

Given the importance of unpaid cancer care, the lack of carer-centric online resources requires urgent attention. Carers should be centrally involved in codesigning website content and design, to ensure acceptability and suitability to its target audience.[10 17] A codesign process was used for conceptualising and implementing an online cancer carer resource in the UK[18] and Vietnam.[19] Common carer issues were elucidated with cancer carers and cancer-specific healthcare professionals (HCPs) to inform construction of the online interventions. This study will follow this methodology.

There is pressing need to develop locally relevant cancer carer resources informed by the collective knowledge of experienced HCPs and carers. Such codesigned resources could assist informal cancer carers to provide effective care in patients' communities, and address burdens associated with unmet carer needs, which increase over time.[7]

Aim and research question

This study is part of a larger project developing a codesigned online resource for Australian informal cancer carers. The aims are to identify strains experienced by urban and rural Australian informal cancer carers, as described by carers and HCPs, and to understand their views about a cancer carer-specific online resource.

METHOD

Study design

The qualitative design reflects the constructivist belief that perceived reality is constructed from individual and socio-historical contexts.[20] A thematic analysis was conducted, using selected grounded theory[21 22] techniques of inductive, comparative and cyclic analysis.[23] Strauss's grounded theory approach supports thematic analyses.[24] Study reporting followed 'Consolidated Criteria for Reporting Qualitative Research' (see online supplemental file 1 for checklist) guidelines.[25]

Patient and public involvement

Two Australian informal cancer carers formed part of the project Steering Committee, and attended regular project update meetings. Their shared experiences, feedback and guidance helped to inform project priorities. All carer participants in this study will be invited to review the new carer website once completed, so that final consumer perspectives could be integrated and amendments made where advised.

Setting and participants

Carers of patients with any form of cancer were recruited from outpatient waiting rooms at one urban and two rural hospitals in Victoria, Australia, with 'rural' defined as areas outside major cities.[26] HCPs were recruited from one urban and one rural hospital. Carer sampling was initially convenience and then purposive to ensure sufficient representation of urban and rural participants. Carer participants were ≥18 years, informal cancer carers and proficient in English. HCPs were providers of clinical and/or supportive care to patients with cancer, with ≥2 years' experience.

Data collection

This was stage 1 of a larger codesign study where the final stage will be the finalisation of the carer website. In this first stage, carers were invited by SMP to attend a focus group seeking information about their caregiving experiences, and recommendations regarding developing a supportive online resource. SMP was not known to, and had no pre-existing relationship with any potential participant. All carers provided informed consent prior to focus group participation. Two focus groups were held, one each in urban and rural settings. Due to the COVID-19 pandemic, further in-person focus groups could not be conducted, and individual telephone interviews were utilised instead, using the same questions/topic outline as the focus groups. Focus group/interview questions were informed by previous work[18] and the research team comprised carers, heath psychologists, behavioural scientists, cancer-specific HCPs and a cancer charity representative. Audiorecorded focus groups and telephone interviews were conducted/moderated by SMP and CB. Both SMP and CB are female project managers and postdoctoral researchers with prior experience in conducting qualitative interviews. SMP and CB summarised content at the end of interviews and focus groups to confirm comprehension of participants' perspectives; this was deemed a more appropriate practice than returning transcripts to participants, given the tendency for interpretation and understanding of content to change over time.[27]
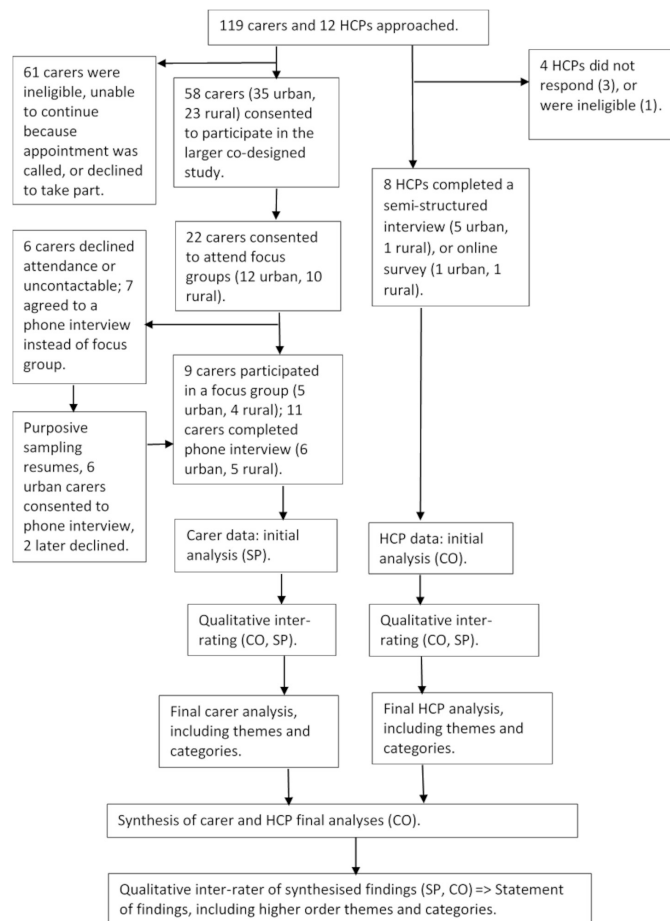
Figure 1 Carer and HCP data analysis schematic. HCP, healthcare professional.

HCPs engaged in a semistructured audiorecorded interview (in-person or telephone) conducted by SMP or an online questionnaire as time permitted. Each HCP provided informed consent prior to their interview. Interview questions invited HCPs' perspectives on carer responsibilities, burdens and well-being; and recommendations for online resource support. See online supplemental file 2 for interview/focus group schedules.

Data analysis
Carer and HCP data were initially separately analysed. Analysis involved coding (labels for text segments), category development (labels for comparable code groups) and development of themes (labels for comparable category groups). SMP initially analysed carer data and CO'C, a female experience qualitative researcher, initially analysed HCP data, assisted by ATLAS.ti (V.8)[28] qualitative data management software. Rigour and reflexivity was achieved through an inter-rater strategy[29] whereby SMP and CO'C examined all data independently and then collaboratively, discussing and reworking the analyses until reaching agreement. Carer and HCP themes and categories were then compared by CO'C to generate higher order themes and categories. SMP reviewed and agreed with the final analysis.

See figure 1 for analysis schematic. Descriptive statistics were calculated for background data.

RESULTS
Sample demographics
Twenty carers (14 female) participated in focus groups (n=9) or interviews (n=11). They cared for 11 males and 10 females (1 cared for 2 people). Carers' relationship to patients included: wife (nine), husband (five), daughter (four), mother and unknown. Patients' primary diagnoses were breast (five), blood (three), head and neck (three), skin (two), pancreas (two), liver, brain, lung, prostate and unknown. Focus groups and interviews were approximately 3–4 hours and 20 min, respectively.

Eight HCPs (six female) participated in semistructured interviews (n=6), or online surveys (n=2). Roles included nursing (three), radiation oncology (two), medical oncology (two), social work and patient/carer engagement.

Four higher order themes and eight higher order categories were identified. Data analysis is illustrated in table 1. In data illustrations, carers C-U1–C-U11 lived in urban and C-R12–C-R20 in rural areas. HCP-U1–HCP-U6 worked in urban and HCP-R7–HCP-R8 in rural areas.

THEMATIC FINDINGS
Theme 1: often unprepared, carers undertake multitudinal challenging responsibilities to alleviate patients' needs
Carers' multitudinal tasks
Carers described playing a 'huge' role in supporting and alleviating patients' multitudinal needs during patients' treatment, survivorship and end-of-life care phases. Described by HCP-U2 as 'non-professional health workers', carers also assume many domestic tasks once performed by patients. Most appeared to be unprepared for the challenging burdens involved. Carers attend to patients' illness and treatment side effects and may assist with, 'showering, shopping, cooking, cleaning' (HCP-R7), paperwork, massages, social engagements and protection from others' demands, including children. For some patients, carers 'do everything' (HCP-R8).

> I'm dealing with tubes, I'm dealing with medication, I'm dealing with vomiting, I'm dealing with defecating, I'm dealing with constipation, … it was really, really difficult learning so much stuff and how to deal with it in such a short length of time. … the hardest change for me was the extra work with business and the house and managing friends. (C-R12)

Many carers emphasised that keeping life as 'normal as possible' (C-U7) assisted coping.

> He just wants everything the way it was… 5:30 every morning, getting his feet on the floor, having breakfast, out the door to work, and that's what keeps him going psychologically and mentally. (C-U1)

Table 1 Illustration of the development of two higher order categories (right column), which informed higher order theme 2: 'carers' biopsychosocial and fiscal strains are affected by patients' hardships and available informal supports'

Quotes	Codes	Categories (separately informed by HCP* & Carer† data)	Themes (separately informed by HCP* & Carer† data)	Higher order categories (in-formed by all data)
There's a huge emotional burden on them in terms of watching that person close to them going through what they're going through. (HP-U4)*	Carer emotionally burdened as observes what patient goes through*	Carers' individualised biopsychosocial and fiscal strains compare with patients' strains*	Carers address patients' multifaceted needs, experiencing strain comparable to patients, affected by available support*	Strains associated with patients' hardships
The impacts are gonna be lots of practical issues, financial issues, emotional, psychological, social, loss of income. I said finance, like significant unmet needs for both the carer as well as the patients. (HP-U2)	Carers and patients share impacts and unmet needs: practical, financial, emotional, psychol, social*			
I was a little bit anxious through the surgeries, my mother had six surgeries and two of them was sixteen hours so I felt anxious, anxious yeah, the name. And during her radio and chemo treatment she was debilitated and was difficult to see that, um, I was strong to deal with that but wasn't, um, it wasn't easy for me. (C-U6)†	Patient's anxiety and debility impacts heavily on the carer†	Carers' emotional, social, physical and financial well-being is adversely affected by patients' hardships†	Carers' emotional, social, physical and/or financial adversity is affected by patients' hardships and available support†	
You feel their pain, you're watching their pain, you're watching their illness. (C-R14)	Carer feels patient's pain†			
It varies a great deal, for some people they're computer literate and will do a lot of searching on the internet. Other people are into talking to families and friends, if there are some other people within their group of family and friends who have gone through cancer treatment. Or they may be coming together with the patient to their medical appointments and getting information from clinicians, from allied health people. But there are also many carers who simply don't have good access. (HP-U3)	Carers variably access support: internet if computer literate; family/friends/allied health if available*	Carers incidentally learn, and acquire reputable and/or harmful cancer-related information*	Carers address patients' multifaceted needs, experiencing strain comparable to patients, affected by available support*	Informal support helps carers if available and suitable
(Carers receive information) from a range of souces, but mainly from the internet. Very often this causes distress and upset as they don't fully understand detials around the diagnosis and they access inforation which is not relevant to the patient's condition (HP-R7)	Information accessed from internet, but often distresses as not relevant*			
The support groups, multiple myeloma, I found that helpful, very interesting. My husband won't attend, but I attend. (C-U1)	Carer recognises the importance of peer support, when accepted†	Family and friends provide emotional and practical support, especially in rural areas†	Carers' emotional, social, physical, and/or financial adversity is affected by patients' hardships and available support†	
I've had a sister that's just gone through breast and brain and lung cancer so she was a wealth of information. (C-R17)	Support from family with previous cancer experience†			

*Includes examples of HCP quotes, codes, lower order categories and lower order themes which informed the higher order categories and theme.
†Includes examples of carer quotes, codes, lower order categories and lower order themes which informed the higher order categories and theme.
HCPs, healthcare professionals.

Challenges supporting patient-to-HCP liaisons

Carers monitor patients' well-being, advocate for healthcare services, transport or share public transport with patients to medical centres and accompany them during challenging waiting periods. C-R17 felt 'lost' waiting 3 months between her husband's diagnostic procedures and treatment, stating, 'It seemed like you waited forever'. Carers usually called HCPs when patients were symptomatic, but described having to manage inconsistent or contradictory information across multiple HCPs.

Carers' confidence, expectations and opportunities related to assisting patient-to-HCP communications widely varied. Comments included: 'You don't like to intervene in an appointment 'cause it's not your illness' (C-R14), and 'You don't want to waste their (HCPs') time' (C-U5). In contrast, some felt their unique understanding about the patient was underacknowledged: 'I've got a bit more to offer than just sitting there like a stoolpigeon' (C-R13). Others were more assertive, or helped patients' assertiveness: 'Tell them the way it is … how much suffering they (patient) actually are doing (sic). So, if he doesn't tell them, I make him tell them' (C-R15). Patient-carer tension, however, could arise when carers 'corrected' patients. Some carers described how HCPs directed conversations towards themselves rather than patients, which 'annoyed' some carers, though others were pleased when patients spoke scarce English or were very unwell.

Many HCPs were concerned about challenges experienced by carers. HCP-U5 suggested that, 'Navigating the different services and systems … can be very overwhelming and can lead to (carer) burn-out'. HCPs also acknowledged distress managed by carers when informing extended family members about patients' conditions.

Theme 2: carers' biopsychosocial and fiscal strains are affected by patients' hardships and available informal supports
Strains associated with patients' hardships
Carers' individualised experiences were affected by sociosituational contexts, health literacy and patients' dependency needs, diagnoses and prognoses. Carers may experience relationship difficulties with patients, personal health issues, other family responsibilities and psychological difficulties, including anxiety, guilt, exhaustion, frustration and stigma. C-R18 described, 'having trouble sleeping' 'cause I worry about what's going on and I cry at the drop of a hat'. Dealing with patients' prognostic uncertainty could be especially stressful. Carers can lose identity, 'becom(ing) someone else completely' (C-R12), and lifestyles can change: 'Everything's come to a stop' (C-R19). Financial burden can arise from additional cancer-related costs and time needed from work. Alternatively, C-R15 returned to work when her husband's employment ceased on his diagnosis. While supporting and witnessing cancer's toll on patients, carers may 'forget about looking after themselves' (HCP-U4) or felt unable. Rural carers explained that they were 'not ready' (C-R19) or 'just haven't got the time' (C-R18) to seek professional help. C-R13 said:

> I felt very, very stressed. (Doctor) said, 'Oh well, I can put you onto any one of a number of local people if you want that', and I didn't take that up, and in a way I didn't have the time to. (C-R13)

Some HCPs believed that carers and patients experience comparable distress, which was reinforced by C-R14 who said, 'My lifestyle improves if his (patient's) lifestyle improves'. Further, it 'maybe harder' being a carer

'because they're bearing the load for two people' (HCP-R8). C-U2 struggled with his wife's 'moods', asking 'How do you handle them? … I can get very fragile myself'. C-R13 also described the challenge of helping his wife to understand 'I'm not going so well either'.

Informal support helps carers if available and suitable
Carers experienced nil to extensive support from family members and friends. Urban dwellers experienced intermittent social support whereas rural dwellers described more emotional and practical support. People, however, may not appreciate carers' stress: C-R13 explained: 'I've got good friends …. And they'll always ask me about my wife and they never ask me about me'.

Helpful cancer-related information could be received from other carers met in waiting areas and known people with previous diagnoses. Some HCPs, however, observed that negative cancer-related stories reported by others could elicit inapplicable fears, leading carers 'further down the rabbit warren of negativity' (HCP-U1).

Theme 3: the carer-neglecting healthcare system elicits discontentment
Health system inadequately supports carers
Most HCPs believed that the healthcare system inadequately supported carers, highlighting that HCPs seldom suggested carer support resources nor understood cancer's impact: 'We often underestimate how involved carers are, and how much they put their own needs aside' (HCP-U5). Carers' statements regularly verified HCP concerns, with reports that medical discussions could be 'unidirectional' and brief. Information received was patient focused: 'We got all the little booklets from (Hospital). But nothing for carers, just all patient related' (C-R15). C-R12 said:

> They expect you to be a pharmacist, and … you can't understand how they possibly think you understand what they're saying because you've been told so much information in such a short length of time and surely they know that you don't have a clue. (C-R12)

There was a belief among HCPs that rural carers were disproportionately disadvantaged by the healthcare system compared with urban carers, where rural carers 'simply don't have good access' (HCP-R7) to acceptable forms of support:

> Everything now is online but it's not gonna work for regional… I have a lot more options… to support a metro-based carer as opposed to a regional carer and that needs to improve. (HCP-U3)

Individual carers were also frustrated by professional support costs. Some rural dwellers were frustrated by distances travelled to metropolitan treatment centres, though an equal number welcomed the leisure experienced on trains:

> I love going down by train, I can sleep and I can do my Sudoku, it's a great service, it's wonderful. (C-R13)

Inadequate access to carer information

Difficulties carers experienced with existing online information included it was 'hard to follow', 'all over the place', needed collation, conflicting and challenging to trust. C-U3 preferred helplines due to difficulties negotiating online technology. Stories from other carers, including online, were widely helpful:

> (Mum) had big abdominal surgery, so I found out online that one of those, um, similar to like a waist trainer would be really good … that's something I wouldn't have found out unless I was talking to other carers online who'd been through this kind of situation. (C-U11)

HCPs believed that most carers had inadequate access to information from reputable organisations and internet sites. HCP-U2 suspected that most carer education occurred 'the hard way. They just discover that, gee this car parking here's expensive … and I was told it'd be fifteen minutes for radiotherapy but we're really here for half the day'.

Theme 4: an accessible, relevant, online cancer carer resource is needed

Online resource needed for diverse, time-limited carers

HCPs and almost all carers agreed that a carer-specific, online resource relevant to a broad range of caregiving circumstances was needed. Individuals emphasised that the accessible resource should support and/or reduce isolation experienced by diverse, time-poor, urban and rural Australian carers. While the online resource was not considered helpful for the computer illiterate, carers' computer literacy was expected to increase, particularly following COVID-19; HCP-U3 said:

> I think COVID-19 has taught us that not everybody can and will be able to come face to face for care so it is important to have online, but at the same time let it not be the only option. (HCP-U3)

Specific presentation recommendations were that the resource should be user-friendly, treat carers 'normally', and include key messages, minimal jargon, quick links to key information, and downloadable information suited to diverse learning styles, including fact sheets, videos, diagrams and pictures. C-U5 liked 'the written summary' and C-R14 suggested nature in interview recordings to inspire housebound carers.

Educative, practical, supportive and reputable content

Table 2 summarises carer and HCP content recommendations. Resource content-related recommendations encompassed educational, practical and supportive information 'relevant to carers' local area(s)' (C-R20). Inclusion of other carers' stories was highlighted because, 'you're connecting with it' (C-R14). Urban and rural carers' recommendations were comparable. Both carers and

Table 2	Content related recommendations for carer-specific online resource	
Content	**Carer recommendations**	**HCP recommendations**
Educational/practical information	► 'Schooling for caregivers… to realise the expectations' (C-U2): practical course that includes 'basic training in tubes… dressings' (C-U1), 'coordinating the medication' (C-R12), etc. ► Food/cooking directions suitable for patients undergoing treatment.	► Stress and crisis management. ► Importance of self-care, including guilt-free breaks. ► Bereavement issues. ► Dealing with boredom. ► How to ask for and accept help. ► Tips for communicating with HCPs.
Illness information	► Information about patients' illnesses 'to be more prepared' (C-U6). ► Symptoms across stages. ► Treatments. ► Palliative care.	
Carer stories	► Experienced carers' stories.	
Supportive Information/links to reputable local supports	► Access to peer-based support. ► Locally based support services/home care and how to access. ► Practical assistance including finding transport support or a wheelchair. ► Care-related advisory services. ► Volunteer support. ► Support groups for varied carer age groups. ► Employment support. ► Already-existing support organisations, for example, helplines. ► Financial services/negotiating aid.	► Information about available support services, for example, social work, counselling, palliative care, respite.

C, carer; HCP, healthcare professional; R, rural; U, urban.

HCPs recommended links to existing reputable support organisations and financial services; carers focused on illness and task related information, while HCPs focused on carers' emotional needs. HCPs also recommended content tailored for Lesbian, Gay, Bisexual, Transgender (LGBT, non-binary sexuality) and non-English speakers.

DISCUSSION

This work built on previous findings that carers felt physically and mentally exhausted due to being ill prepared when taking on the multitudinal array of role-related responsibilities.[18] They also experience innumerable strains, such as risk of burnout,[30] and loss of identity.[31] A key finding building on this literature was that the Australian healthcare system neglects carers whereby carers actively seek relevant information but are frequently met with confusing, conflicting or difficult to navigate informational sources, or none at all. HCPs also confirmed that there is minimal or no ongoing support for carers from health services. Importantly, all HCPs and almost all carers supported the development of a carer-specific online resource tailored to meet carer needs.

Interestingly, the study found that availability of social support varied between rural and urban carers, with urban carers reporting more unmet supportive needs. The finding that rural carers experienced greater lay support compared with urban carers reinforces previous findings,[32–34] and may challenge perceptions of social isolation in rural areas.[35] Rural carers in our study were found to be active seekers and receivers of emotional and practical support from friends and family, more so than urban carers. There were, however, some indications that rural carers were reluctant, or felt unable, to seek professional support for themselves. HCPs in our study spoke of the comparative lack of access to acceptable forms of professional support, which has been reported previously,[33] and may help to explain the slow uptake of these services by carers in rural areas. When appropriate professional psychosocial services are offered to rural carers, these services tend to be well accepted and valued.[33] For those who are reluctant to access professional support, previous research has demonstrated the capacity of supportive websites in motivating cancer patients and their carers to seek professional help when needed,[10] highlighting the positive impact that such resources can have.

A minor finding was that some rural carers were not burdened by the distances travelled to receive care, partially contradicting findings that carers experience significant burdens in having to travel great distances to and from healthcare providers.[32] Our study found that while some carers acknowledged the burden of distance, an equal number of carers were grateful for the reprieve that long travel by train allowed. However, this finding may be due to improvements in rural infrastructure, and the comparatively smaller size of Victoria compared with larger Australian states/territories where rural population densities are lower.

Carers expressed a need for greater well-being advice for themselves, and practical advice/guidance from HCPs, or peers in similar circumstances. Interestingly, while HCPs emphasised the need for well-being and self-care advice for carers to be prominent on the website, carers urged for illness and task-oriented information that would assist them in providing better care for the patient. This may suggest that carers perceive their well-being as secondary to that of the patient. Both carers and HCPs acknowledged that while an online resource was valuable and needed, its utility would be limited to those who are computer literate. While computer literacy is increasing, some will struggle with this form of learning and engagement, suggesting that traditional forms of information and help-seeking (eg, face-to-face consults or phone-based helplines) will continue to be needed. As such, there is a parallel need for healthcare providers to assess whether carers require such assistance as part of the patient's ongoing cancer care.

Study limitations

Carers were approached in hospital waiting rooms, therefore, perspectives are from those able to travel to healthcare services. Perspectives from carers unable to attend hospital appointments are not represented, potentially skewing the results towards those who experience fewer barriers when accessing services. The COVID-19 pandemic also presented challenges regarding how data were collected. Focus groups provide an opportunity to delve into content raised via group discussion, which may not be present during a one-on-one telephone interview. In the absence of such a sounding board, there may be a disconnect between individual perspectives and the 'group consensus'. Because of this, further investigation to verify these findings is needed. Also, though this study aimed to identify broad informational and supportive content that should be included in a new online resource, the type of content needed by the carer may vary depending on the type and stage of cancer experienced by the patient. Continued research with larger, more representative samples could clarify whether broad informational and supportive content provides comparable assistance to carers, as diagnosis-specific and stage-specific content. A larger sample size could also help to confirm the findings in this study, relating to the differences in informational and supportive needs between rural and urban cancer carers in Australia. While data saturation was not achieved due to time restraints, limited resources, as well as the inherent complexity of the area, the study still provides much varied and important information about challenges and needs that carers endorse, and recommendations for how best to support them. The findings provide sufficient information to inform the development of an online carer-specific resource.

Clinical implications and future directions

This study presents the first phase in codesign methodology for assessing informal carer needs in an Australian

healthcare system that frequently overlooks the impact and importance of carers in cancer care. Findings reflect key stakeholders' perspectives for the design of a carer-specific online resource, acting as a new 'one-stop-shop' for both evidence-based cancer information, as well as peer-driven motivational and informational content to improve feelings of connectedness and confidence, and reduce feelings of isolation. Best practice in patient care in cancer should involve parallel and continued assessments of carer support needs from diagnosis through to bereavement (eg, what to expect during palliative care). Policies and procedures that link carers with peer-driven supportive and/or respite services in their local areas could encourage self-care, and reduce stress and boredom. Online and offline approaches that champion patient and carer advocacy could encourage carers to seek social and professional support when needed, potentially alleviating any psychological impacts related to caregiving.[36 37] Valued initiatives such as monitored online chat forums or phone support services that provide 24/7 access to counselling and basic caregiving advice specific to cancer (eg, managing common treatment side effects) were inferred from participants in this study. These options could present viable solutions to address social isolation and improve confidence in caregiving, particularly given the ongoing impact of COVID-19.

Future research involving larger samples and more rural/urban locations is needed in order to support the findings here, given the modest sample size. Research exploring different recruitment methodologies with carer populations could also address the inherent difficulties of establishing representative cohorts in this area. Lastly, the codesigned approach described in this study could be adopted in future research assessing gaps in information and service provision relevant to other chronic illnesses, to inform the design of meaningful and effective resources.

CONCLUSIONS

Rural and urban carers, and HCPs, endorsed the development of an Australian, carer-specific online resource. Advice and information will be informed by expert knowledge and advice from key stakeholders, whose views have been summarised here. Importantly, recommendations from rural and urban carers were comparable, indicating resource generalisability. The development of this resource is an important next step, so that its efficacy in delivering meaningful content for carers can be assessed.

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