

1 **“I'm not the one with cancer but it's affecting me just as much”: A qualitative study of**
2 **rural caregivers’ experiences accessing support for their health and wellbeing while**
3 **caring for someone with cancer**

4 **Abstract**

5 Family and friends provide vital support to people with cancer but often report feeling
6 unsupported themselves. This study investigated rural caregivers’ experiences of accessing
7 support for their health and wellbeing while caring for someone with cancer. Through semi-
8 structured interviews, 20 rural caregivers described their experiences seeking support for their
9 health and wellbeing while caring for someone with cancer, including what support was, or
10 would have been, helpful. Interview transcripts were analysed using content analysis to
11 identify types of support sought and what aspects of support were helpful or unhelpful. Rural
12 caregivers reported seeking practical, medical, and psychosocial support for their health and
13 wellbeing. Caregivers’ responses reflected facilitators and barriers to seeking support as well
14 as the benefits and challenges associated with accessing support (i.e., what was helpful and
15 unhelpful). Facilitators to seeking support included telehealth options and being included in
16 patient care discussions. Barriers included having to navigate complex government and
17 healthcare systems alone and caregivers’ needs for support not being acknowledged or
18 understood by medical staff or social networks. Benefits of accessing support included help
19 with managing daily responsibilities and links to additional avenues of support. Challenges
20 included delays in receiving support and the support not meeting caregivers’ needs, adding to
21 their caregiving load. To optimise rural caregivers’ access to support for their health and
22 wellbeing, support services should be prompt and flexible in delivery, simple to navigate,
23 integrated with patient care, improve caregivers’ ability to cope, provide access to additional
24 avenues of support, and reduce caregiver burden.

25 **Keywords:** caregivers, oncology, qualitative research, regional and remote, supportive care

26 **Introduction**

27 Cancer is a leading cause of morbidity and mortality worldwide, and this burden is
28 expected to expand in the coming decades with increasing cancer incidence (Sung et al.,
29 2021). In Australia, over 90% of people diagnosed with cancer receive regular support from
30 an informal caregiver, usually a family member or close friend (Ugalde et al., 2021). This
31 support can include assistance with domestic tasks, personal care and medications,
32 transportation to and from appointments, managing finances, and emotional support (Given et
33 al., 2017; Litzelman, 2019; Wyatt et al., 2017). Family and friends play a key role in cancer
34 survivors' recovery, with the presence of a caregiver linked to better physical, functional, and
35 emotional wellbeing for the cancer survivor (Adashek & Subbiah, 2020).

36 For caregivers, the demands of caregiving often impacts their health and wellbeing,
37 including reduced diet quality and physical exercise (Beesley et al., 2011; Ezendam et al.,
38 2019; Johnston, Collins, et al., 2024), and elevated anxiety, stress, and depression (Lund et
39 al., 2014; Papastavrou et al., 2009; Unsar et al., 2021). Moreover, despite the vital support
40 they provide to cancer survivors, caregivers often report feeling unsupported themselves
41 (Kim & Carver, 2019). Caregivers report that their needs can be deprioritised by health
42 professionals, who do not tend to screen caregivers for potential psychosocial distress or offer
43 referrals to support (Taylor et al., 2021). Amongst healthy lifestyle programs designed for
44 people affected by cancer, few have specifically included caregivers (Ellis et al., 2021;
45 Johnston, Ayre, et al., 2024). Caregivers also describe difficulty finding time to seek support
46 for their health and wellbeing amidst the additional responsibilities of caregiving (Taylor et
47 al., 2021).

48 Previous research has identified a need for targeted support for caregivers living
49 outside of a major city (Gunn et al., 2022; Ugalde et al., 2019). Compared to people of the
50 same age in the general population, rural caregivers experience lower mental health-related

51 quality of life, particularly those with higher caregiver burden and chronic illness (Goodwin
52 et al., 2022). Rural caregivers also report unmet needs for support with practical concerns
53 (e.g., accessing transportation and accommodation), their physical and mental wellbeing, and
54 information to support them in their caregiving role (Stiller et al., 2021).

55 To date, there is limited knowledge regarding rural caregivers' experiences in
56 accessing support specifically for their own health and wellbeing. When it comes to accessing
57 cancer-related support in general, previous research indicates that people living in rural areas
58 experience several challenges, including fewer local services, greater travel distances, and
59 higher costs (Barlow et al., 2022; Paul et al., 2013; Taylor et al., 2021). Many rural cancer
60 patients and caregivers also experience financial stress from reduced participation in paid
61 employment post-diagnosis (Johnston et al., 2023). Previous research indicates that when
62 rural caregivers do seek support for themselves, it is commonly sought from general
63 practitioners and online sources (Johnston et al., 2022), potentially reflecting the increased
64 accessibility and convenience of these sources compared to others. However, the same study
65 showed that at least one in three rural caregivers had not sought any form of support for their
66 health and wellbeing.

67 This study therefore aimed to understand the experiences of rural caregivers seeking
68 support for their own health and wellbeing while caring for someone with cancer, including
69 what support was helpful and what would have been helpful. Research findings can be used
70 to improve the accessibility and acceptability of support services for rural caregivers.

71 **Methods**

72 *Participants and recruitment*

73 This study was part of a larger project examining how caring for someone with cancer
74 affects the health and wellbeing of rural caregivers. Participants, recruitment, and other data
75 collected through this project have been published elsewhere (Johnston, Collins, et al., 2024).

76 Briefly, adults (aged 18 years or older) providing informal support to someone with a cancer
77 diagnosis who could speak and understand English and provide informed consent were
78 eligible to participate. Participants were recruited over a 12-month period from multiple
79 channels. Eleven participants were recruited through advertising at [blinded for peer review]
80 accommodation lodges. [Blinded for peer review] lodges are located in [blinded for peer
81 review] and offer subsidised accommodation to cancer patients and their caregivers traveling
82 more than 50 kilometres (31 miles) for cancer treatment. The remainder were recruited
83 through an existing longitudinal study led by the research team (n=6), word of mouth (n=2),
84 and a private Facebook group (n=1). The study was approved by the Human Research Ethics
85 Committee of [blinded for peer review] (Approval # here).

86 *Data collection*

87 This study used a qualitative approach to capture rich and detailed accounts of rural
88 caregivers' experiences accessing support for their health and wellbeing. Individual semi-
89 structured interviews were conducted via telephone using a guide developed by the research
90 team and pilot-tested with two caregivers (see **Supplementary Table 1**). Before conducting
91 the interviews, the first author underwent training for managing distressed research
92 participants. The first author had no prior relationship with participants and obtained written
93 or verbal consent from all participants prior to interviewing. Average duration of the
94 interviews was 30 minutes (range 12 to 52 minutes), with a total of 10.5 hours recorded.
95 Audio recordings were transcribed verbatim for analysis.

96 This paper reports on data collected in the second half of the interview regarding the
97 support used by rural caregivers for their health and wellbeing, including what support was
98 helpful, and what would have been helpful. To describe the study sample, the interview
99 concluded with questions about the caregiver's age, postcode of residence, relationship to the

100 person with cancer, time since the person's most recent cancer diagnosis, and cancer type.
101 Postcode of residence was used to determine level of geographical remoteness using the
102 Australian Statistical Geography Standard Remoteness Structure (Australian Bureau of
103 Statistics, 2018).

104 *Data analysis*

105 Participant characteristics were extracted from transcripts and summarised using
106 descriptive statistics. Content analysis was used to analyse the data collected in the interview
107 regarding rural caregivers' support-seeking for their health and wellbeing. Content analysis is
108 a qualitative method involving the systematic coding of text based on the words and language
109 used (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). It therefore uses an inductive approach
110 to generate key concepts from the data. Interview transcripts were first reviewed to identify
111 sections where the caregiver spoke about seeking support for their own health and wellbeing.
112 These sections were then coded in two rounds to firstly identify the type of support sought
113 (e.g., transport assistance, general practitioner, close friend) and then to identify what aspects
114 of the support were helpful or what would have been helpful. Codes that shared a similar
115 meaning were grouped together and informed the key concepts presented below. Coding
116 continued until no further codes could be extracted and the data could be sorted into existing
117 codes without any discrepancies or overlap. Participant quotes are presented to illustrate the
118 analytic findings, alongside the caregivers' relationship to the person with cancer.

119 *Researcher characteristics and reflexivity*

120 The research team is comprised of health behaviour researchers, with qualifications in
121 dietetics and psychology, and an experienced cancer support advisor. Our recent work
122 identified that caring for someone with cancer can negatively impact rural caregivers' health
123 behaviours, particularly sleep, social connection and leisure, and accessing healthcare when

124 needed (Johnston, Collins, et al., 2024). Thus, considering our professional backgrounds and
125 work, we recognise that an underlying assumption in this study is that caregivers would
126 benefit from accessing support for their health and wellbeing while caring for someone with
127 cancer. However, this view was challenged in some ways through this analysis which
128 identified that for some rural caregivers, seeking support for their health and wellbeing was
129 not a beneficial experience, and only added to their caregiving load. This highlights the
130 importance of directly consulting with rural caregivers to ensure that support is designed and
131 delivered in a way that meets their needs and minimises additional burden.

132 **Results**

133 Key characteristics of the 20 rural caregivers who completed an interview in this
134 study are summarised in **Table 1**. Most caregivers were the spouse or partner (n=13; 65%) of
135 the person they were caring for, or another family member (n=6; 29%) or neighbour (n=1;
136 5%). Time since the patient's most recent cancer diagnosis ranged from 2 months to 10 years
137 (median 3 years). Rural caregivers in this study were caring for people with a wide range of
138 cancer types, including head and neck (n=5; 25%), gynaecological (n=4; 20%), breast (n=3;
139 15%), skin (n=3; 15%), gastrointestinal (n=2; 10%), brain (n=1; 5%), blood (n=1; 5%) and
140 lymphoma (n=1; 5%). Caregivers' ages ranged from 31 to 71 years (median 58 years), 50%
141 were male, and all lived in an inner or outer regional area as classified by the Australian
142 Bureau of Statistics (Australian Bureau of Statistics, 2018).

143 [INSERT TABLE 1 HERE]

144 ***Domains of support accessed by rural caregivers for their health and wellbeing***

145 Rural caregivers reported seeking support for their health and wellbeing across three
146 domains: practical, medical, and psychosocial (see **Figure 1**). In the practical domain, rural
147 caregivers sought support with meals or cooking, transport, laundry, accommodation, and

148 finances from government, healthcare, and community services. Support sought in the
149 medical domain included medical advice for themselves and their role as a caregiver from
150 general practitioners and healthcare professionals in hospitals and private treatment centers.
151 Finally, in the psychosocial domain, rural caregivers sought support for their mental, social,
152 and emotional health and wellbeing from counsellors, psychologists, Indigenous health
153 officers, social workers, support advisors, other cancer survivors (i.e., peer support), family,
154 and friends.

155 [INSERT FIGURE 1 HERE]

156 When asked about their experiences seeking support for their health and wellbeing,
157 rural caregivers often responded to this question in relation to the patient rather than
158 themselves. As described previously, our interview questions explicitly asked caregivers
159 about what support they accessed for themselves, and what was, or would have been, helpful.
160 We found that rural caregivers described both the process of *seeking* support (i.e., what
161 enabled and hindered access to support), and the quality of support received (i.e., what was
162 helpful and unhelpful about the support accessed). Thus, in analyzing rural caregivers'
163 responses about seeking support for their own health and wellbeing, four distinct concepts
164 were identified as defined below:

- 165 • **Facilitators** referred to factors that *enabled access* to support.
- 166 • **Barriers** referred to factors that *hindered access* to support.
- 167 • **Benefits** referred to aspects of the *support* accessed that were *helpful*.
- 168 • **Challenges** referred to aspects of the *support* accessed that were *unhelpful*.

169 As shown in **Figure 1**, these concepts were mutually exclusive and applicable across all
170 domains of support sought. Findings for each concept are presented below.

171 ***Facilitators to accessing support for health and wellbeing***

172 A key factor that enabled rural caregivers to seek practical and psychosocial support
173 for their health and wellbeing was being able to access this support through the
174 accommodation center they were staying in while the person they were caring for underwent
175 treatment in a major city. For example, rural caregivers who stayed in accommodation lodges
176 owned by a cancer support organization had access to a support advisor and a communal
177 kitchen during their stay. Both these services supported them to look after their health and
178 wellbeing:

179 *“I’ve reached out to the support advisor at the lodge – I recognise that this time*
180 *round, I’m just not coping, so he’s put me on to a counsellor.” (Mother)*

181 *“Since we’ve moved to the lodge [in the city], we’ve been eating a lot better... We’re*
182 *close to the communal kitchen, which is really good.” (Female partner)*

183 Staying in a major city during cancer treatment also facilitated access to medical
184 support for rural caregivers that was local and affordable:

185 *“We’ve found a GP [general practitioner] across the road from where we’re staying*
186 *in the city... We just Googled and found one that bulk billed, and yeah, we found a*
187 *really good doctor that was within five minutes.” (Female partner)*

188 For other rural caregivers, telehealth enabled them to continue accessing their usual
189 medical and psychosocial care while travelling for treatment:

190 *“I Skype [video call] with my psychologist. I have an OT [occupational therapist]*
191 *who I do phone calls with and my doctor... I see him regularly as well, like at least*
192 *once a month. He’s done everything through telehealth, even my scripts and stuff.”*
193 *(Daughter)*

194 For some rural caregivers, the patient’s care team facilitated caregivers’ access to
195 support for their health and wellbeing by providing important information on what to expect
196 to both the caregiver and patient. This meant caregivers did not need to seek this support
197 elsewhere:

198 *“A lot of people say differently, but I found that the support we were getting and the*
199 *information I was receiving both from my wife’s doctors and also the nursing staff in*
200 *oncology – they were absolutely wonderful, very informative. They spoke a lot about*
201 *other peoples’ experiences and things like that, what we could expect ... I didn’t*
202 *really have to turn to my own doctor or any sort of support to manage getting through*
203 *it all.” (Husband)*

204 ***Barriers to accessing support for their health and wellbeing***

205 Rural caregivers reported several factors that hindered their ability to access support
206 for their health and wellbeing. The need to navigate complex government and healthcare
207 systems alone was a barrier to accessing practical support, such as lodging and transport
208 assistance. The process of identifying relevant support and obtaining access to this support
209 was burdensome and added to their caregiving load, with some caregivers describing feeling
210 unheard and unsupported by support providers:

211 *“Mum knew how hard it was going to be [finding accommodation] and she knew it*
212 *wasn’t going to be achievable, so she actually wanted to give up and not have*
213 *chemotherapy. I really had to fight the systems and say, this isn’t okay... There was*
214 *just an expectation for me, the carer, to pull all this together.” (Daughter)*

215 *“We have had so much trouble with [support service]. Quite a few times I had to take*
216 *someone with me to do the paperwork... They make you feel so bad that you’re asking*
217 *for help.” (Husband)*

218 Rural caregivers also described situations where medical and psychosocial support
219 could be available to them, but their needs were not acknowledged. This impacted caregivers'
220 wellbeing particularly when they had an acute need for support:

221 *"The treatment centre has never asked, 'How are you going? Are you coping okay?*
222 *Do you need to be linked in with any supports?' Nothing. Absolutely nothing from*
223 *them over the last five years... They are doing great wonders with my husband and*
224 *he's a part of quite a lot of research, but as for me, they don't give a s***. They need*
225 *to worry about the carers because they're the ones getting the patient through."* (Wife)

226 *"I think the conclusion that I've come to from all this is if people do ring, they ring*
227 *and they check in on my mum, who has cancer. They don't ever check in on my son or*
228 *me."* (Daughter)

229 Geographical isolation from family and friends while travelling for treatment, or not
230 having close contacts nearby, also impeded caregivers' access to social support:

231 *"I felt isolated from family [in the city] because most of our family is up here [at*
232 *home], but we did have some friends down there [in the city] ... so we sort of kept in*
233 *touch."* (Husband)

234 *"My wife's family live overseas and my family live in another state... we had a few*
235 *friends that could help out, one week here, one week there, but really we've been by*
236 *ourselves."* (Husband)

237 In some cases, rural caregivers minimised interactions with their social networks to
238 avoid excessive sympathy or concern from others as these interactions amplified caregivers'
239 emotional burden:

240 *“We only told a couple friends who are unconnected to the other friends, you know*
241 *what I mean. We just decided to go that way because my wife said, ‘I don’t want*
242 *people constantly asking questions and feeling sorry for me’.” (Husband)*

243 *“I found that I wasn’t answering the phone, and I wasn’t leaving the house, because if*
244 *I ran into people they’d say, ‘How are you?’, ‘How’s your daughter?’ And then,*
245 *that’s it, I’d just start crying. So, for about three weeks, I just shut myself away.”*
246 *(Mother).*

247 For some rural caregivers, relationships with family and friends had been strained by
248 the stress of cancer or were estranged prior to the diagnosis. Consequently, it was difficult to
249 access support from their social networks:

250 *“A lot of worry has been on my wife’s mum and dad and tensions cue up, because I*
251 *had to have those confronting conversations with her parents. I know we’ve gotta all*
252 *be positive, but we’ve also gotta think of reality too. What happens if...?” (Husband)*

253 *“My wife has three sisters, and they didn’t make an effort to show any compassion or*
254 *help out at all... Our kids come down and stayed for a week or two at the start, but*
255 *you know, they have to go back for work... Some people just think, that’s not our*
256 *problem. Let them worry about it.” (Husband)*

257 *“No one’s even offered a meal or made any intentions of coming to see us. My*
258 *husband’s sister hasn’t even phoned once... I’ve been able to work out real quick who*
259 *cares and who doesn’t. And the reality is, not many people do.” (Daughter)*

260 Several other barriers to accessing support were identified by rural caregivers. These
261 barriers were not specific to a domain of support, and included a “grin and bear it” attitude in
262 their role as a caregiver:

263 *“No use whingeing and crying about it, cause there’s nobody to listen to you or talk*
264 *to about it. I just sort of bundle it up and do it myself. Yeah. They call it old school.”*

265 *(Male partner)*

266 *“I was busy and just not focusing on all the negative stuff, which a lot of people do*
267 *suffer from when they’re caring for someone with an illness like that.” (Husband)*

268 Rural caregivers were also unsure of where to seek support and did not know what
269 support was available to them:

270 *“Who’s to know [what support is available]. As a patient, you know who can help you*
271 *out, but as a caregiver or partner or whatever, you don’t really know.” (Husband)*

272 *“I’m not the one with cancer but it’s affecting me just as much, and I’ll be the one*
273 *picking up the pieces and all the rest after the fact... I can’t see the support for the*
274 *caregiver after the death of the cancer patient and it is a big issue.” (Husband)*

275 ***Benefits of accessing support for their health and wellbeing***

276 Across all domains, support that was sensitive and responsive to their needs helped
277 rural caregivers to continue engaging with the support despite their changing circumstances
278 and needs:

279 *“I’ve been keeping in contact with my GP [general practitioner], and she*
280 *understands. She goes, ‘What dose of anxiety tablets should I put you on? It sounds*
281 *like you’re going through a bit, I might up the dose on that.’” (Sister)*

282 *“I work my social life around Mum. If she’s having a bad day, I won’t really do*
283 *anything. I’ve got really wonderful friends that’ll be like, ‘That’s alright, we’ll wait*
284 *for you’. They wait until I’m ready.” (Daughter)*

285 For some rural caregivers, a key benefit of accessing practical and psychosocial
286 support was that it reduced the caregiver's load by attending to their daily activities or
287 helping them to manage these responsibilities. For some, this enabled them to focus on
288 supporting their loved one with cancer:

289 *"I think everyone at the lodge has been very supportive. Not having to stress about*
290 *the rent every week – honestly, it's been fantastic. We've been able to just worry*
291 *about my husband's health and focus on him getting better."* (Female partner)

292 *"I have a friend looking after my place, animals, and grass, plants, which is good."*
293 (Husband)

294 *"How lovely is it to have washing facilities here at the lodge... I know that sounds like*
295 *a stupid thing to say but it's the thing that keeps growing around you all the time.*
296 *Being able to do that conveniently is a blessing."* (Sister)

297 When accessing support in the medical and psychosocial domains, receiving kindness
298 and care from the support provider helped rural caregivers to feel acknowledged and valued:

299 *"I can't walk past the reception office without the lodge staff saying, 'Are you*
300 *alright? Is everything okay?' ... I get more support from this centre than I do my own*
301 *family."* (Sister)

302 *"The Indigenous officers, they've actually helped huge, too [sic]. I can just go*
303 *downstairs and have a yarn with them."* (Daughter)

304 *"I can't complain about the doctors... they've all got time for you even though they're*
305 *flat out."* (Husband)

306 In the psychosocial domain, rural caregivers reported that connecting with other
307 caregivers experiencing similar challenges helped them to cope with their own situation and
308 expanded their available support network:

309 *“We used to sit on the patio in the afternoon and have drinks with our neighbors [at*
310 *the lodge]. Because we’re here so long we got to know them... you get to know people*
311 *going through the same predicament as your family. We’d just sit and have a drink*
312 *and laugh [...] It’s a whole new family you make.” (Male partner)*

313 *“Because other people at the lodge were going through exactly the same thing... it*
314 *sort of became like a family, if you like. That was really quite nice, actually.”*
315 *(Husband)*

316 Finally, for some rural caregivers, accessing psychosocial support for their health and
317 wellbeing resulted in including additional avenues of support they were previously not aware
318 of. Access to this additional support was in turn facilitated through help with navigating entry
319 into the other service:

320 *“Just feel so lucky to have the social worker, because she linked me up with this place*
321 *[the lodge]. She’s been amazing. She knew I was getting a little stir crazy with my*
322 *family. She was like, let me ring them [the lodge staff], let me talk to them and we’ll*
323 *find out what’s going on.” (Daughter)*

324 ***Challenges of accessing support for their health and wellbeing***

325 Rural caregivers who accessed practical support reported that, at times, this support
326 did not meet their needs, thereby adding to their caregiving load. For example, rural
327 caregivers described difficulties accessing food while staying in accommodation in major
328 cities:

329 *"There's plenty of support [at the lodge], it's just the practical things... Frozen meals*
330 *would be a great option because they'd be quick to heat up... I can't be bothered*
331 *travelling all the way to the grocery store and by the time I bring the groceries back,*
332 *it's late and I've been at the hospital all day."* (Mother)

333 Additionally, while caregivers were able to access subsidised travel, this practical
334 assistance did not meet their needs when poor coordination of the patient's treatment and
335 follow-up appointments resulted in unnecessary travel and increased caregiver stress:

336 *"We've been a mess for probably eight weeks now since the diagnosis, because there's*
337 *just so many inconsistencies and people trying to bully us into travelling back and*
338 *forth."* (Daughter)

339 *"The hospital has provided all the transport which is fabulous... but there's too many*
340 *plane trips... one time we had to go down for an MRI [magnetic resonance imaging]*
341 *only, and then fly back. It was like, couldn't you have done the MRI and the CAT*
342 *[computerised axial tomography] scan and the pathology in one day, so we didn't*
343 *have to do 18 plane trips? Because that's a huge amount of money... that sort of*
344 *streamlining would be beneficial for the carer, the person with cancer, and the*
345 *taxpayer's budget."* (Female neighbour)

346 Some caregivers experienced delays in receiving support, particularly financial
347 support and primary care from a GP in their rural community:

348 *"I'm in the process of organizing to be on a carer payment... you've got to wait three*
349 *months until you receive a payment, so I've just been living off my tax money and my*
350 *savings."* (Female partner)

351 *“In regional areas, it takes a week to get an appointment with a doctor, regardless of*
352 *how urgent it is. So, it’s very hard to get a doctor’s appointment.” (Female*
353 *neighbour)*

354 For some caregivers, although they were able to access and benefit from psychosocial
355 support, the duration of support available to them was inadequate as they required ongoing
356 support:

357 *“I’m using [a psychologist] right now, but I’ve only got two sessions left that have*
358 *been paid by a support service and I have found them incredibly helpful.” (Husband)*

359 Further, some rural caregivers felt that psychosocial support providers who did not
360 have a lived experience of caring for someone with cancer were unable to provide effective
361 support:

362 *“You want someone to vent to. You’re better getting in touch with other people that*
363 *are in the same boat... not a counsellor. The counsellor’s got no idea. Unless you’re*
364 *going through this, you’ve got no idea how it feels.” (Husband)*

365 **Discussion**

366 In this qualitative study, rural caregivers described their experiences seeking practical,
367 medical, and psychosocial support for their health and wellbeing while caring someone with
368 cancer. These experiences included the facilitators and barriers to accessing this support, as
369 well as the benefits and challenges of the support provided. Findings from this study provide
370 practical recommendations for how healthcare professionals, community organisations, and
371 policymakers can optimise the design and delivery of support services for rural caregivers, a
372 group that is vulnerable to experiencing poor mental wellbeing and unmet needs for practical
373 assistance (Goodwin et al., 2022; Stiller et al., 2021).

374 This study identified that the process of accessing support for health and wellbeing
375 while caring for someone with cancer can be burdensome and often adds to rural caregivers'
376 load. While some caregivers do not need or want support, like those who expressed a 'grin
377 and bear it' attitude in the current study, barriers to accessing support may, in part, explain
378 the recent research finding that a third of rural caregivers had not sought support for
379 themselves (Johnston et al., 2022). Findings from our study reinforce calls for better
380 navigational support for rural caregivers, a gap in existing education programs for cancer
381 caregivers (Papadakos et al., 2022). For example, practical assistance with navigating
382 government and healthcare systems and guidance on where to seek support or what is
383 available could address many of the barriers and challenges identified by rural caregivers in
384 the current study. Further, caregivers in our study who were able to access support for their
385 own health and wellbeing reported being linked with additional avenues of support by service
386 providers. This suggests that navigational support to gain access to relevant services can
387 facilitate ongoing and future use of support.

388 Most of the factors that facilitated access to support for rural caregivers in our study
389 were encountered while staying in a major city for cancer treatment. These facilitators
390 included being able to talk to a support advisor while staying in accommodation run by a
391 cancer support organisation and the availability of local and affordable options for healthcare
392 in the city. Few facilitators to accessing support for their own health and wellbeing were
393 specifically located in their local communities indicating there may be a need to increase the
394 reach of in-person and telephone-based support for rural caregivers (Gunn et al., 2021).
395 Further, when rural caregivers were able to access support for themselves, delays in receiving
396 support and inadequate duration of support limited the benefit for rural caregivers' health and
397 wellbeing. These findings suggest further work may be needed to improve accessibility and
398 availability of support in rural areas, particularly when most caregiving tasks are undertaken

399 at home (van Ryn et al., 2011). Additionally, rural caregivers in our study often relied on
400 subsidised services, such as accommodation and mental health support, but these services
401 were often cost or time-limited. Increasing the reimbursement amount or duration of support
402 covered by these services may improve accessibility since many rural caregivers reduce or
403 cease participation in paid employment while caring for their loved one (Johnston et al.,
404 2023; Kent et al., 2023).

405 Inattention to rural caregivers' needs was a key barrier to, and challenge associated
406 with, accessing support for their health and wellbeing. For example, caregivers reported
407 being in medical settings where support could be available to them, but their needs were not
408 acknowledged, or the support offered did not meet their needs. Similar experiences have been
409 reported by cancer caregivers in other studies, including feeling like they had limited
410 opportunity to express their need for support with healthcare professionals (Mosher et al.,
411 2015; Taylor et al., 2021). The rural caregivers in our study who were included in patient care
412 discussions had access to informational support regarding what to expect as a caregiver and
413 felt appreciated because their caring role was acknowledged and valued. While there are
414 several organizational challenges to achieving this, such as limited time and resources within
415 healthcare settings (Griffin et al., 2022), review evidence indicates that including caregivers
416 in patient care discussions can result in better health outcomes for both patients and
417 caregivers (Fiest et al., 2018) and models of care that better integrate informal caregivers has
418 been identified as a research priority (Kent et al., 2016). Together with our findings, we
419 propose that including and valuing the role of caregivers in patient care discussions is a low
420 cost, but high impact, support that healthcare professionals can provide to caregivers within
421 the constraints of time-limited appointments.

422 Outside of healthcare settings, rural caregivers often sought support for their health
423 and wellbeing from interpersonal relationships, although experiences accessing this support

424 were complex. While some rural caregivers received practical support from family and
425 friends that reduced their caregiving load, others avoided seeking support from family and
426 friends to minimise the burden of sympathy from others or because these relationships had
427 been strained by the stress of the cancer diagnosis (or were strained prior to diagnosis). Rural
428 caregivers in other studies have reported similar experiences, including having to manage
429 concerns from family and friends who regularly inquire about the person with cancer and
430 feeling socially isolated when people distanced themselves following the patient's diagnosis
431 (Kent et al., 2023). For rural caregivers in our study, talking to other caregivers in similar
432 situations was beneficial as it helped them cope with their own challenges and expanded their
433 available support network, particularly when support from family and friends was not
434 available (e.g., while travelling for treatment) or not offered. Previous research reports that
435 formal peer support programs can provide effective psychosocial support and practical self-
436 care knowledge for family caregivers, often filling gaps in support from medical staff and
437 social networks (Joo et al., 2022). Seeking support from other cancer caregivers may also
438 reduce the 'burden of sympathy' encountered when caregivers sought seeking support from
439 family and friends who were not coping with the caregivers' situation. Thus, empowering
440 rural caregivers to connect with peers may be an effective means of 'lightening the load';
441 however, these programs require appropriate matching and training of peer supporters and
442 monitoring to ensure ongoing benefits for both parties (Joo et al., 2022).

443 *Strengths and limitations*

444 This study included a diverse sample of rural caregivers, including a broad range of
445 ages, relationships, time since the patient's diagnosis and cancer types. The qualitative
446 approach used grounded this analysis in participants' own words. While the focus on rural
447 caregivers is a key strength of this study, none of the caregivers lived in remote or very
448 remote areas. It is likely that caregivers living in geographically isolated areas may

449 experience additional facilitators, barriers, benefits, and challenges to accessing support for
450 their health and wellbeing that were not captured in this study. Future research involving
451 longitudinal, population-wide surveys could provide more detailed information on rural
452 caregivers' needs and experiences accessing support for themselves, changes over time, and
453 priority areas for intervention.

454 *Conclusion*

455 For people living in rural areas, seeking support for their health and wellbeing while
456 caring for someone with cancer can be burdensome, particularly when access to support
457 requires navigating complex systems alone, their needs for support are not acknowledged or
458 understood by medical staff and social networks, and delivery of support is delayed. On the
459 other hand, rural caregivers benefit from support when it is sensitive and responsive to their
460 needs, acknowledges and values their caregiving role, and expands their support network. To
461 optimise rural caregivers' access to support for their health and wellbeing, support services
462 should be prompt and flexible in delivery, simple to navigate, integrated with patient care,
463 improve caregivers' ability to cope, provide access to additional avenues of support, and
464 reduce caregivers' daily load.

465

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467 **Conflict of Interest Statement:** The authors declare that there are no conflicts of interest.

468 **Data Availability Statement:** The data that support the findings of this study are available
469 on request from the corresponding author. The data are not publicly available due to privacy
470 or ethical restrictions.

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