

## Research Article

# The Impact on Employment for Rural Cancer Patients and Their Caregivers Travelling to Major Cities for Treatment

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**Purpose.** A cancer diagnosis significantly impacts daily life, particularly for those living outside of major cities who must travel to receive cancer treatment. This study investigated the impact of cancer and travelling for treatment on the employment of rural cancer patients and their caregivers. **Methods.** Cancer patients staying in subsidised accommodation lodges in Queensland, and their nominated caregivers, described employment status prior to diagnosis in a structured interview. Three months later, they answered several open-ended questions about the impact of cancer and travelling for treatment on their employment. Descriptive statistics and thematic analysis were used to report and analyse responses. **Results.** Of 308 rural cancer patients in paid employment pre-diagnosis, 70% reported a change in employment post-diagnosis, with 62% of these patients no longer working. Many of those still employed post-diagnosis required extended leave, flexible working arrangements, and a gradual return to work, particularly for those experiencing ongoing treatment side effects. Of the 102 rural caregivers in paid employment prior to the patient's diagnosis, 56% reported a change in employment after diagnosis, with 37% of these caregivers no longer working. Many caregivers were unable to work while at the lodge, except for those with flexible or remote work arrangements and low caregiver burden. Financial stress from loss of income and limited support in returning to work were common experiences. **Conclusions.** Disruptions to employment are common for people in rural areas affected by cancer. Support from employers is vital, including offering tasks that can be completed remotely or require less physical effort.

## 1. Introduction

A cancer diagnosis and its treatment can have a significant impact on daily life, including participation in paid

employment [1]. In a population-based study in the United States, many cancer survivors reported needing to take time off, reduce hours, or change roles following their diagnosis [2]. Employment is recognised as a key social

determinant of health, and disruptions to employment, including reduced work productivity and loss of income, can have significant social and financial implications for cancer survivors [3, 4]. In a longitudinal study in the United States (US), people with a prior cancer diagnosis reported a greater number of workdays missed due to poor health, as well as higher expenditure on healthcare, compared to those without a cancer diagnosis [5]. Although returning to work after a cancer diagnosis can be challenging [6], cancer survivors report a range of benefits, including opportunities for personal growth, social connection, normalcy, and routine [7]. Therefore, initiatives to support the health and well-being of cancer survivors should consider strategies for supporting cancer survivors to maintain their participation in paid employment or return to work as able.

The impact of cancer and its treatment on employment also extends to informal caregivers (i.e., family and friends) who support the person diagnosed with cancer. Caregivers' support often involves more than 40 hours of direct care per week, including assistance with activities of daily living, medical care and follow-up, and emotional and social support [8]. This caregiving load can require caregivers to adjust their employment arrangements to support the cancer patient through their treatment and recovery [9]. Like cancer patients, these changes to work can have significant social and financial implications for the caregiver [10].

For people living in rural areas, a cancer diagnosis often requires travelling to a major city to receive cancer treatment. Being away from home for treatment, often for extended periods, presents a challenge to rural cancer patients and their caregivers who are in paid employment [11]. In a study of cancer caregivers, those living in rural areas were more likely to report taking time off work, less income, difficulty paying bills, trouble meeting day-to-day expenses, and using their savings compared to caregivers living in urban areas [12]. Furthermore, a large proportion of Australia's agricultural workers and farmers live in rural areas [13], occupations typically associated with owner-operator businesses relying on unpaid family workers [14]. Therefore, a cancer diagnosis and the need to travel for treatment are likely to be highly disruptive for these people and their broader family [15]. With approximately two-thirds of the value of Australia's exports coming from agriculture and farming in rural areas [16], it is vital that we understand the impact of cancer and its treatment on the employment of rural cancer patients and their caregivers.

Despite the apparent challenges and disparities, little is known about the employment-related experiences of rural cancer patients and their caregivers after a cancer diagnosis [1]. Therefore, this study investigates changes to employment for rural cancer patients and their caregivers following a cancer diagnosis and the impact that cancer and travelling for treatment has on their employment. Research findings can contribute to future initiatives to support people living in rural areas whose careers and livelihoods may be impacted by a cancer diagnosis.

## 2. Materials and Methods

**2.1. Participants and Recruitment.** This paper uses data from a longitudinal cohort study, Travelling for Treatment, that tracked patient-reported outcome measures across time (up to 5 years from study recruitment). Data from this study have been reported in several other publications [17–20]. Recruitment for the Travelling for Treatment study was conducted between September 2017 and June 2020. Adults, who had a cancer diagnosis or were undergoing tests for cancer, staying at one of Cancer Council Queensland's (CCQ) subsidised accommodation lodges were invited to participate in the study. Invitation packs were distributed upon arrival by lodge staff or, if this was not possible (e.g., after hours check-in), were sent via mail to their home addresses. Cancer patients were encouraged to nominate one informal caregiver (i.e., their spouse/partner, family member, or friend) to be invited to the study. A research volunteer contacted patients and caregivers by phone one week after pack distribution to follow-up on the invitation to participate and to answer any questions.

To stay at CCQ's accommodation lodges, cancer patients must have to travel over 50 kilometres (31 miles) to receive cancer treatment in Queensland. The cost of their stay is subsidised through the Patient Travel Subsidy Scheme and so is essentially free for cancer patients and any accompanying family. Cancer patients and caregivers were eligible for inclusion in this analysis if they consented to participate in the Travelling for Treatment study (or, as per ethical approval, had implied consent:  $n=9$  patients), were aged 18 years or older, and able to read and understand English. Eligible cancer patients and caregivers were included in this analysis if they completed the interview at study recruitment (see Supplementary Figure 1). Ethical approval was obtained from a recognised institutional Human Research Ethics Committee (H17REA152).

**2.2. Data Collection.** This mixed methods analysis uses quantitative and qualitative data collected in the first two timepoints of the Travelling for Treatment study. In that study, participants completed a structured interview and a written questionnaire at baseline (i.e., at recruitment, often during their first visit to the lodge). Follow-up questionnaires were sent three months after baseline, again at 12 months, and then annually for up to five years post-baseline. This paper reports on data collected in the structured interview and written questionnaire at baseline, and the follow-up questionnaire that was sent three months later.

**2.2.1. Sociodemographic Characteristics.** Participants' age, gender, education, relationship status, cancer type (patients only), and relationship with patients (caregivers only) were recorded in the baseline written questionnaire. Residential street address was geocoded and mapped to the 2011 Statistical Area Level 2 (SA2) boundaries using MapMarker® Australia Version 15.16.0.21 and MapInfo Pro® Version 15.0. SA2 was used to classify caregivers by remoteness and relative socioeconomic advantages and disadvantages

[21, 22]. Participants were considered “rural” if they lived outside of a major city area according to the SA2 classifications.

**2.2.2. Employment Status Prior to Diagnosis.** During the baseline interview, participants were asked about their employment status prior to their cancer diagnosis or the diagnosis of the patient for whom they were caring. Responses were categorised as full-time (>30 hours per week), part-time/casual, volunteer, unemployed, retired, or others. Participants were also asked, “Has your employment status changed since you were diagnosed with the current cancer?” (or since the patient was recently diagnosed with cancer). If yes, participants were asked, “Please provide details of the change.” The participant’s occupation prediagnosis was also recorded during the interview. Occupations were subsequently coded for industry of work and categorised as either “Rural” (e.g., farming, agriculture, maintenance, and infrastructure) or “Other” (e.g., health, education, administration, and retail). Occupations were also coded according to whether they required manual labour (yes/no).

**2.2.3. Impact of Cancer and Travelling for Treatment on Employment.** In the follow-up questionnaire sent three months after baseline, participants were asked to “Please provide any further details on how your cancer or travelling to the lodge has reduced your ability to work.” Participants were also asked to “Please provide any details on how travelling to the lodge has reduced your ability to participate in other aspects of your lifestyle, such as hobbies, chores, and social activities.” For both these questions, an open field box (3 lines) was provided for their comments. At the end of the questionnaire, participants were asked, “Do you have any further comments to add about your cancer, travelling for treatment, or your experience at the Cancer Council accommodation lodge?” A space was provided (approx. half a page) for their responses. All responses relevant to employment provided across these three questions were extracted and included in this analysis.

**2.3. Data Analysis.** Descriptive statistics were used to summarise employment status prediagnosis and changes to employment postdiagnosis for (a) cancer patients, (b) caregivers, and (c) patient-caregiver dyads (where both the cancer patient and their nominated caregiver participated in the study). Chi-square tests were used to compare the sociodemographic characteristics of patients and caregivers by paid work prediagnosis (yes vs. no), changes to work postdiagnosis (no change vs. any change), and work cessation postdiagnosis (no vs. yes). The latter two comparisons only included patients and caregivers who reported being in paid employment prediagnosis. All analyses were performed using SAS, version 9.4 (SAS Institute, Cary, North Carolina) with a  $p < 0.05$  (two-sided) cut-off for statistical significance.

Patients’ and caregivers’ comments regarding the impact of cancer and travelling for treatment on employment were analysed using codebook thematic analysis to identify

recurring patterns in the data. As described by Braun and Clarke, codebook thematic analysis is distinct from their reflexive approach to thematic analysis; the codebook thematic analysis refers to a structured approach to coding that conceptualises the themes as topic summaries (i.e., themes are based on content rather than meaning) [23]. First, a member of the research team reviewed the database of comments extracted from the follow-up questionnaire to familiarise themselves with the data. Comments were then coded inductively based on the words used by participants to describe their experience, grounding the development of themes within the original data. Codes were documented in a coding framework alongside representative participant quotes for each code. Initial themes were generated by grouping codes based on their similarities and differences, ensuring each theme represented a distinct concept in relation to the impact of cancer and travelling for treatment on employment for rural cancer patients and their caregivers.

A second researcher reviewed the extracted comments, coding framework, and themes generated for coherence. Themes were then refined by the two researchers to identify the essence of each theme and the overall story from the data. Where relevant, differences in interpretation were discussed and a consensus reached. The final themes are presented below alongside participant quotes to illustrate the analytic findings. For context, participants’ industry of work, manual labour requirement, and age at diagnosis (by decade) are reported beside each quote.

### 3. Results

**3.1. Sample Characteristics.** Of the 811 rural cancer patients who consented to participate, 708 completed the baseline interview (Supplementary Figure 1). Those excluded due to missing data on their employment status prediagnosis ( $n = 103$ ) were less likely to have completed tertiary education (Supplementary Table 1). Key characteristics of the 708 rural cancer patients included in this analysis are shown in Table 1. The sample included a diverse range of cancer types, including breast (18%), head and neck (15%), skin (12%), prostate (12%), and gynaecological (9%). Twelve rural cancer patients did not have a confirmed cancer diagnosis but had travelled to a major city for cancer-related tests. At baseline, rural cancer patients were, on average, 6 months postdiagnosis (IQR 3 to 21 months, range 0 to 17 years). Of the 708 rural cancer patients, 564 (80%) completed the follow-up questionnaire three months later.

Of the 259 rural caregivers who consented to participate, 211 completed the interview (Supplementary Figure 1). There were no significant differences in sociodemographic characteristics between caregivers included in this analysis and those excluded due to missing data on the employment status prediagnosis ( $n = 48$ ) (Supplementary Table 2). Key characteristics of the 211 rural caregivers are shown in Table 2. At baseline, rural caregivers had been caring for someone with cancer for a median of 9 months (IQR 5 to 21 months, ranging from 2 weeks to 13 years). Of the 211 rural caregivers, 192 (91%) completed the follow-up questionnaire three months later.

TABLE 1: Baseline characteristics of rural cancer patients by paid work prediagnosis ( $n = 708$ )<sup>a</sup>.

	Total sample ( $n = 708$ ) $N$ (%)	Paid work prediagnosis		$\chi^2$	$p$ value
		Yes ( $n = 325$ ) $N$ (%)	No ( $n = 383$ ) $N$ (%)		
Gender					
Male	368 (53%)	166 (53%)	202 (53%)	0.0569	0.8
Female	326 (47%)	150 (47%)	176 (47%)		
Age					
<65 years	334 (48%)	227 (72%)	107 (28%)	131.7595	<0.0001
≥65 years	359 (52%)	88 (28%)	271 (72%)		
Education					
Secondary school or below	397 (58%)	169 (54%)	228 (62%)	4.6092	0.03
Vocational/university	285 (42%)	145 (46%)	140 (38%)		
Area-level disadvantage (SEIFA)					
Low (≤50th percentile)	578 (82%)	266 (82%)	312 (82%)	0.0255	0.9
High (>50th percentile)	126 (18%)	57 (18%)	69 (18%)		
Geographical remoteness (ARIA)					
Major city/inner regional <sup>b</sup>	347 (49%)	139 (43%)	208 (55%)	9.3444	0.002
Outer regional/remote	357 (51%)	184 (57%)	173 (45%)		
Relationship status					
In a relationship	425 (64%)	216 (66%)	236 (62%)	1.7862	0.2
Not in a relationship	256 (36%)	109 (34%)	147 (38%)		
Cancer type					
Breast	125 (18%)	75 (23%)	50 (13%)	23.1480	0.002
Skin	83 (12%)	33 (10%)	50 (13%)		
Head and neck	107 (15%)	48 (15%)	59 (15%)		
Prostate	82 (12%)	29 (9%)	53 (14%)		
Gynaecological	61 (9%)	19 (6%)	42 (11%)		
Others	230 (32%)	110 (34%)	120 (31%)		
Unknown	10 (1%)	4 (1%)	6 (2%)		
No diagnosis	10 (1%)	7 (2%)	3 (1%)		

<sup>a</sup>Subgroups do not total  $n = 708$ ,  $n = 325$ , or  $n = 383$  where there are missing data. <sup>b</sup>A small percentage (<4%) of patients were classified as living in a major city according to the Australian Bureau of Statistics classification system [22]. They are included in this sample of rural cancer patients because they were required to travel at least 50 kilometres to receive treatment in a city centre. ARIA: Accessibility/Remoteness Index of Australia. SEIFA: Socio-Economic Indexes for Areas.

**3.2. Changes to Employment for Rural Cancer Patients after a Cancer Diagnosis.** Of the 708 rural cancer patients, 325 (46%) were in paid employment prediagnosis. Of those in paid employment prediagnosis, 218 (67%) reported working full-time and 107 (33%) part-time or casual. Of the 383 rural cancer patients who were not in paid employment prediagnosis, 325 (85%) reported being retired, 39 (10%) unemployed, and 19 (5%) were undertaking volunteer work (Figure 1). Rural cancer patients in paid work prediagnosis were more likely to be aged less than 65 years, have completed tertiary education, and live in an outer regional or remote area (Table 1).

Of the 325 rural cancer patients in paid employment prediagnosis, 308 had data on changes to employment postdiagnosis. Most ( $n = 217$ ; 70%) reported a change to work postdiagnosis (Figure 1), with 62% of rural cancer patients in this group no longer working (of these, 75% stopped work and 25% retired). Rural cancer patients who reported a change to work but were still employed ( $n = 82$ ) had taken leave (57%), reduced hours (15%), changed role (7%), or reported a change to work without providing specific information (21%). Compared to rural cancer patients who reported no change to employment postdiagnosis, those who reported a change were more likely to live in an inner regional area (48% vs. 34%,  $\chi^2 = 5.1536$ , and

$p = 0.02$ ) (Supplementary Table 3). Compared to rural cancer patients who did not stop work postdiagnosis, those who stopped working were more likely to be male (59% vs. 54%,  $\chi^2 = 4.8794$ , and  $p = 0.03$ ) aged over 65 years (33% vs. 23%,  $\chi^2 = 4.2723$ , and  $p = 0.04$ ), live in a relatively disadvantaged area (89% vs. 76%,  $\chi^2 = 8.2135$ , and  $p = 0.004$ ), and employed in a farming, infrastructure, or maintenance job (55% vs. 42%,  $\chi^2 = 4.9935$ , and  $p = 0.03$ ) (Supplementary Table 4).

**3.3. The Impact of Cancer and Travelling for Treatment on Employment for Rural Cancer Patients.** Of the 325 rural cancer patients in paid employment prediagnosis, 115 provided a relevant comment in response to the three open-ended questions on the follow-up questionnaire about the impact of cancer and travelling for treatment on work. Table 3 outlines the four themes identified regarding the impact of cancer and travelling for treatment on rural cancer patients' employment, including a sample of participant quotes to illustrate each theme. Rural cancer patients reported having to stop work while receiving cancer treatment due to the impact of the cancer and its intensive treatment schedule on their physical health (Theme 1). Rural cancer patients also reported being unable to work due to being

TABLE 2: Baseline characteristics of rural caregivers by paid work prediagnosis ( $n = 211$ )<sup>a</sup>.

	Total sample ( $n = 211$ ) $N$ (%)	Paid work prediagnosis		$\chi^2$	$p$ value
		Yes ( $n = 103$ ) $N$ (%)	No ( $n = 108$ ) $N$ (%)		
Gender					
Male	81 (39%)	44 (44%)	37 (35%)	1.4958	0.2
Female	125 (61%)	57 (56%)	68 (65%)		
Age					
<65 years	106 (52%)	77 (78%)	29 (28%)	51.3589	<0.0001
≥65 years	98 (48%)	22 (22%)	76 (72%)		
Education					
Secondary school or below	111 (55%)	38 (39%)	73 (70%)	19.3394	<0.0001
Vocational/university	92 (45%)	60 (61%)	32 (30%)		
Area-level disadvantage (SEIFA)					
Low (≤50th percentile)	165 (78%)	78 (76%)	87 (81%)	0.7207	0.4
High (>50th percentile)	46 (22%)	25 (24%)	21 (19%)		
Geographical remoteness (ARIA)					
Major city/inner regional <sup>b</sup>	116 (55%)	54 (52%)	62 (57%)	0.5283	0.5
Outer regional/remote	95 (45%)	49 (48%)	46 (43%)		
Relationship status					
In a relationship	185 (91%)	91 (91%)	94 (91%)	0.0043	0.9
Not in a relationship	18 (9%)	9 (9%)	9 (9%)		
Relationship to patient					
Spouse/partner	165 (82%)	72 (75%)	93 (88%)	9.2938	0.01
Other relative	25 (12%)	19 (20%)	6 (6%)		
Other nonrelative	12 (6%)	5 (5%)	7 (7%)		
Cancer type of person they care for					
Breast	38 (18%)	22 (21%)	16 (15%)	10.4239	0.1
Skin	27 (13%)	14 (14%)	13 (12%)		
Head and neck	26 (12%)	13 (13%)	13 (12%)		
Prostate	25 (12%)	5 (5%)	20 (19%)		
Gynaecological	20 (9%)	9 (9%)	11 (10%)		
Other	71 (34%)	38 (37%)	33 (31%)		
Unknown	4 (2%)	2 (2%)	2 (2%)		

<sup>a</sup>Subgroups do not total  $n = 211$ ,  $n = 103$ , or  $n = 108$  where there is missing data. <sup>b</sup>A small percentage (<4%) of caregivers were classified as living in a major city according to the Australian Bureau of Statistics classification system [22]. They are included in this sample of rural caregivers because they were required to travel at least 50 kilometres to receive treatment in a city centre. ARIA: Accessibility/Remoteness Index of Australia. SEIFA: Socio-Economic Indices for Areas.

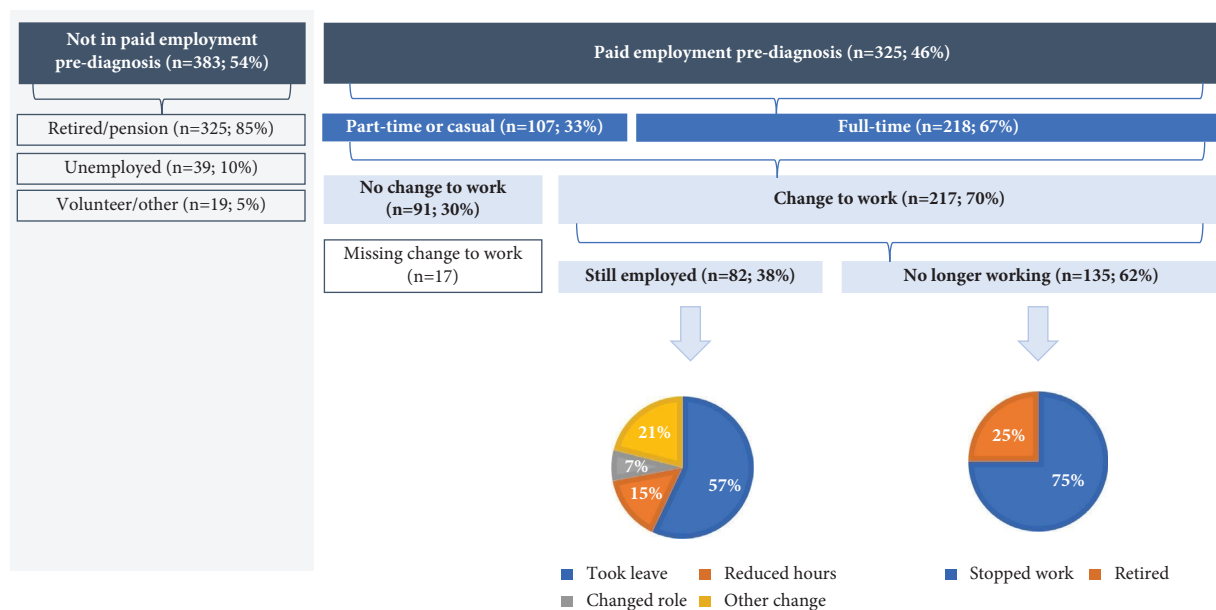
FIGURE 1: Employment status of rural cancer patients prior to their diagnosis and changes to employment postdiagnosis ( $n = 708$ ).

TABLE 3: Themes identified from responses to open-ended questions about the impact of cancer and travelling for treatment on employment for rural cancer patients and their caregivers.

Theme	Sample of participant quotes to illustrate the theme <sup>a</sup>
<i>Rural cancer patients</i>	
(1) Unable to work due to the cancer diagnosis and treatment schedule	<p>"Daily radiation prevented me from working. The cancer itself stopped me from working due to recovery after surgery and extra treatments and appointments" (#346, administration, no manual labour, and aged 40–49)</p> <p>"Receiving daily treatments for 6 weeks. I was unable to work for duration of treatment. I have been unable to work since surgery either" (#287, administration, no manual labour, and aged 30–39)</p> <p>"I retired from work when I got sick. . . I do not feel fit enough to have full-time work." (#64, farming, manual labour, and aged 50–59)</p> <p>"Being 2.5 hours away I was not able to work during treatment" (#466, retail, no manual labour, and aged 40–49)</p> <p>"I couldn't work [while receiving treatment] as I was a fly in fly out worker" (#564, industry unknown, and aged 40–49)</p> <p>"Self-employed farmer. . . absent from work" (#297, farming, manual labour, and aged 60–69)</p> <p>"I have to take four days a fortnight off to travel and receive treatment." (#101, infrastructure, manual labour, and aged 40–49)</p> <p>"Limited access to work by having to drive to and from home to the lodge. Additional leave needed when treatments were delayed or when appointments changed or went over time." (#102, industry unknown, and aged 40–49)</p> <p>"Lose work time for travel and treatment, generally three days" (#320, infrastructure, manual labour, and aged 70–79)</p> <p>"More sick days off work than the normal person to attend appointments" (#241, health, manual labour, and aged 50–59)</p> <p>"I seem to be very tired after treatment and have also lost conditioning so am unable to physically do what I once did." (#544, administration, manual labour, and aged 60–69)</p> <p>"I work on a farm – I can't lift weights I used to or sit in a tractor for long periods of time, and I certainly can't work in the cattle yards." (#465, farming, manual labour, and aged 50–59)</p> <p>"I am constantly tired and have difficulty concentrating plus poor memory recall." (#548, administration, no manual labour, and aged 40–49)</p> <p>"Can only work 3 hours. Soon I get dizzy. Have headaches." (#256, retail, manual labour, and aged 60–69)</p>
(2) Unable to work due to being away from home for cancer treatment	
(3) Reduced ability to work after cancer treatment due to decline in physical health	

TABLE 3: Continued.

Theme	Sample of participant quotes to illustrate the theme <sup>a</sup>
(4) Support from employer for changes to work	<p>"My employer has been fantastic in letting me have extended periods off work for treatment." (#115, industry unknown, and aged 50–59)</p> <p>"At present I am only able to work 3.5 hours per week. I am gradually building up these hours." (#506, education, no manual labour, and aged 40–49)</p> <p>"I only travel into my office 2 days per week – I work from home the rest of the week" (#46, administration, no manual labour, and aged 50–59)</p> <p>"I got exhausted very quickly. I am on a return-to-work plan with my employer. I am not working on the day after my immunotherapy treatments." (#463, education, no manual labour, and aged 50–59)</p> <p>"Agreed on a return-to-work plan with doctor and boss – modified work conditions. No heavy lifting." (#481, infrastructure, manual labour, and aged 50–59)</p>
Rural caregivers	<p>"I work in a remote community, so I was unable to work during my stay." (#566, industry unknown, and aged 50–59)</p> <p>"I work in a hospital—I have been unable to return to that work." (#653, health, manual labour, and aged 50–59)</p> <p>"My work was 1600 kms away while I was at the lodge to support my daughter." (#788, education, no manual labour, and aged 60–69)</p>
(1) Unable to work due to being away from home for treatment	<p>"Many of the issues involving feelings of helplessness are due more to financial worries rather than my wife's cancer (she is about to lose her income protection and is not yet fit to return to work)." (#591, creative arts, no manual labour, and aged 50–59)</p> <p>"Eight months without income is extremely hard. Bills keep on coming, food needs to be bought, rates paid, etc." (#588, industry unknown, and aged 60–69)</p> <p>"I haven't worked for six months because I am caring for my husband. We are living off our savings which are dwindling." (#653, health, manual labour, and aged 50–59)</p> <p>"Being self-employed and travelling back and forth to the city disrupted and possibly lost me work at times, so financially it costs extra for food in the city and buses, taxis, trains, etc. However, we have been so grateful for the accommodation at the lodge, as we were staying at motels before we found out about the lodges." (#607, infrastructure, manual labour, and aged 40–49)</p>
(2) Financial stress due to loss of income	<p>"Having never dealt with Centrelink, I can't figure it out. Pages of forms, no-one will answer the phone. Waiting for ages to speak to someone to be told nothing. ... I have given up. It is enough to deal with my husband slowly deteriorating. ... Having a person at the Cancer Council to assist with navigating the very confusing process would've been amazing." (#653, health, manual labour, and aged 50–59)</p> <p>"I am back at work but it's not a normal situation, working on call, no family support due to the area. Being segregated from my wife during treatment has been extremely difficult. Support for the caregiver at home is very limited and support in general has been limited." (#612, infrastructure, no manual labour, and aged 40–49)</p>
(3) Limited support with finances or returning to work	

TABLE 3: Continued.

Theme	Sample of participant quotes to illustrate the theme <sup>a</sup>
(4) Minimal disruptions to employment due to flexible work or lower caregiver burden	<p>"I am self-employed and used my computer and the Internet – I was able to continue working while staying at the lodge." (#591, creative arts, no manual labour, and aged 50–59)</p> <p>"It is a small disruption to routine, and I take the laptop with me." (#764, administration, no manual labour, and aged 50–59)</p> <p>"I own and operate a corporate mentoring company. If I didn't have understanding clients, I would have struggled" (#603, administration, no manual labour, and aged 60–69)</p> <p>"I was only down there [at the lodge] a couple of days per week supporting my wife, so it wasn't a big deal work wise." (#765, farming, manual labour, and aged 60–69)</p>

<sup>a</sup>Brackets after each quote include the participant's ID number, industry of work, manual labour requirement, and age at diagnosis (by decade).



away from home for cancer treatment as this often required regular or extended periods of leave (Theme 2). The impact of cancer and its treatment on employment continued after treatment was completed, with rural cancer patients reporting reduced capacity to work posttreatment due to loss of physical health and function (Theme 3). In particular, fatigue, reduced strength, and difficulty concentrating affected their ability to work posttreatment. Finally, rural cancer patients identified that support from their employer to accommodate changes to their work was crucial (Theme 4). This included support for taking extended leave during treatment, flexible working arrangements, and a gradual return to work, particularly for those experiencing decline in physical health.

**3.4. Changes to Employment for Rural Caregivers after the Patient's Cancer Diagnosis.** Of the 211 rural caregivers, 103 (49%) were in paid employment prior to the cancer diagnosis. Of those in paid employment prediagnosis, 72 (70%) reported working full-time, 28 (27%) part-time or casual, and 3 (3%) were self-employed. Of the 108 rural caregivers not in paid employment prediagnosis, 96 (89%) were retired, 9 (8%) unemployed, and 3 (3%) were undertaking volunteer work (Figure 2). Rural caregivers in paid work prediagnosis were more likely to be aged less than 65 years, have completed tertiary education, and less likely to be the spouse or partner of the person they were caring for (Table 2).

Of the 103 rural caregivers in paid employment prediagnosis, 102 had data on changes to employment postdiagnosis. Just over half ( $n = 57$ ; 56%) reported a change to work postdiagnosis, with 37% of rural caregivers in this group no longer working (of these, 62% stopped work, 38% retired) (Figure 2). Rural caregivers who reported a change to work but were still employed had reduced hours (31%), taken leave (28%), changed role (11%), or reported a change to work without providing specific information (30%). Compared to rural caregivers who reported no change to employment postdiagnosis, those who reported a change were more likely to be employed in a job prediagnosis that required manual labour (58% vs. 30%,  $\chi^2 = 7.5503$ , and  $p = 0.006$ ) (Supplementary Table 5). Compared to those who did not stop work postdiagnosis, rural caregivers who reported stopping work postdiagnosis were more likely to be over 65 years (43% vs. 16%,  $\chi^2 = 7.2893$ , and  $p = 0.007$ ) (Supplementary Table 6).

**3.5. The Impact of Cancer and Travelling for Treatment on Employment for Rural Caregivers.** Of the 103 rural caregivers in paid employment prediagnosis, 34 provided a relevant comment in response to the three open-ended questions on the follow-up questionnaire about the impact of cancer and travelling for treatment on work. Table 3 outlines the four themes identified regarding the impact of cancer and travelling for treatment on rural caregivers' employment, including a sample of participant quotes to illustrate each theme. Like patients, many rural caregivers indicated that the need to travel to a major city for cancer treatment

disrupted their employment as they were unable to bring their work with them (Theme 1). Where work was a family-owned business back home, other family members had to manage the workload in their absence. Rural caregivers commonly indicated that the cancer diagnosis resulted in loss of income and additional costs, and this caused significant financial stress (Theme 2). One caregiver noted the financial burden was eased by the opportunity to stay in subsidised accommodation. However, rural caregivers commonly reported limited financial support and assistance with returning to work (Theme 3). Rural caregivers indicated a need for improved support in both these areas, including better systems for accessing financial support and community support for returning to work. In contrast, rural caregivers with flexible work arrangements or fewer caregiving responsibilities reported less disruption to employment as they were able to continue working while staying at the lodge or manage their workload around their caregiving commitments (Theme 4).

**3.6. Patient-Caregiver Dyads.** In this sample, 209 patient-caregiver dyads had data on employment prediagnosis. At least one person was employed prediagnosis in 130 (62%) of these dyads (32% both patients and caregivers, 13% patients only, and 17% caregivers only). Among the 65 dyads with data on changes to work, 53 (82%) reported a change to work postdiagnosis (40% both patients and caregivers, 28% patients only, and 14% caregivers only). Among the 72 dyads with data on work cessation, 32 (44%) reported stopping work postdiagnosis (15% both patients and caregivers, 24% patients only, and 6% caregivers only).

Among patient-caregiver dyads in this sample, there was no significant difference in the proportion of patients and caregivers employed prediagnosis (46% vs. 49%,  $\chi^2 = 0.5537$ , and  $p = 0.5$ ). Compared to caregivers, patients were more likely to report a change in work postdiagnosis (70% vs. 56%,  $\chi^2 = 7.3400$ , and  $p = 0.007$ ) and more likely to report stopping work postdiagnosis (44% vs. 20%,  $\chi^2 = 18.0129$ , and  $p < 0.0001$ ).

## 4. Discussion

This study provides novel insight into the impact that a cancer diagnosis has on rural patients and their caregivers who travel to major cities for treatment. Study findings have identified several opportunities for support at various levels, including employers, healthcare professionals, community, and policymakers, to minimise the impact of travelling for treatment on employment for rural cancer patients and their caregivers. These opportunities for support are summarised in Figure 3 and discussed further below.

After a cancer diagnosis, most rural cancer patients and over half of the caregivers in our study reported reduced participation in paid employment. Both patients and caregivers reported that being away from home, due to the need to travel for treatment, affected their ability to work. Of the rural cancer patients who reported a change to employment postdiagnosis, many had stopped working. Among those

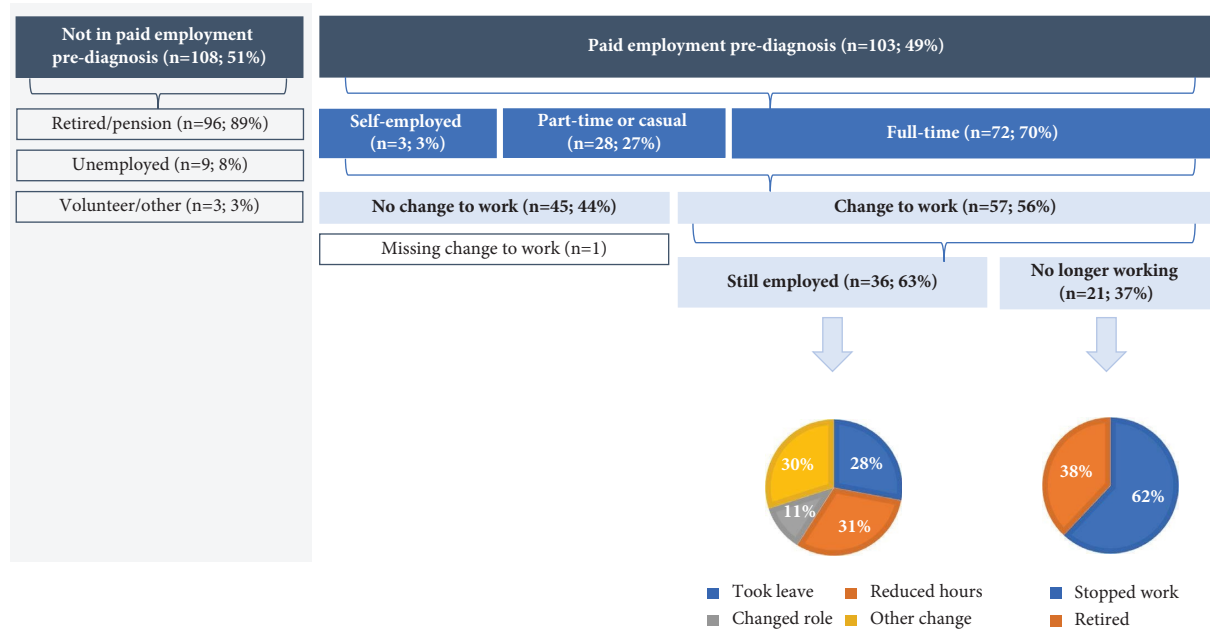


FIGURE 2: Employment status of rural caregivers prior to the cancer patient's diagnosis and changes to employment postdiagnosis ( $n = 211$ ).

still employed, many had taken leave. In contrast, many caregivers continued to be employed postdiagnosis but had reduced work hours, taken leave, or changed roles. Although both patients and caregivers experienced disruptions to employment following a cancer diagnosis, the impact of cancer and its treatment was different for patients and caregivers.

Over 60% of rural cancer patients who reported a change to employment postdiagnosis were no longer working, a significantly higher proportion when compared to caregivers. The intensive and systematic nature of cancer treatment can have a significant impact on cancer patients' physical health as well as their ability to participate in employment [24]. In a survey in the United States (US), cancer patients missed an average of 26 workdays per year to receive cancer treatment and 18 workdays per year due to the side effects of their treatment [25]. In our study, rural cancer patients reported that treatment side effects, including fatigue, reduced muscle strength, and difficulty concentrating, affected their ability to return to work. Many jobs in rural areas involve manual labour [26], which poses an additional challenge to rural cancer patients continuing in paid employment, particularly for those who experience a decline in physical health due to cancer and its treatment [15]. This was observed in the current study, where cancer patients who reported stopping work postdiagnosis were more likely to be working in a farming, agriculture, infrastructure, or maintenance job pre-diagnosis than those who continued working postdiagnosis.

Previous research among cancer survivors in general has highlighted the importance of support from employers for maintaining participation in paid employment postdiagnosis, including practical support, sufficient sick leave, and a plan for returning to work [27]. Similarly, participants in the current study indicated that they valued support from employers for

extended leave during treatment, flexible working arrangements, and a staged return to work posttreatment. The latter was particularly important for those, who may not be able to return to work in the same capacity as prediagnosis, with ongoing physical effects posttreatment. In Australia, it is a legal requirement for employers to accommodate employees with illness or disability, including making reasonable adjustments so they can continue working [28]. For cancer patients who wish to continue in paid employment postdiagnosis, findings from this study can be used to guide these efforts. For example, the need for alternative modes of work postdiagnosis, such as tasks that can be completed remotely or that require less physical effort. These findings regarding the impact of cancer and its treatment on rural cancer patients highlights that employers should be encouraged to consult with rural cancer patients regarding their specific needs for support with employment. Indeed, communication with employers while absent from work due to cancer has been associated with a better return to work experience [29]. Employers could therefore ensure clear and reliable communication channels are available to employees who must take leave from work for cancer treatment.

Many caregivers in this study continued in paid employment after the patient's diagnosis. This suggests that caregivers may be managing the need to work to support themselves and the cancer patient financially while also navigating their additional caregiving responsibilities. Although our study did not investigate reasons why rural caregivers did or did not maintain their participation in paid employment postdiagnosis, caregivers commonly reported financial stress due to the additional costs associated with cancer and its treatment. In a scoping review of studies assessing the financial cost of caring for someone with cancer, the average out of pocket costs were estimated to be \$447 Canadian dollars (CADs) per month, and the cost of

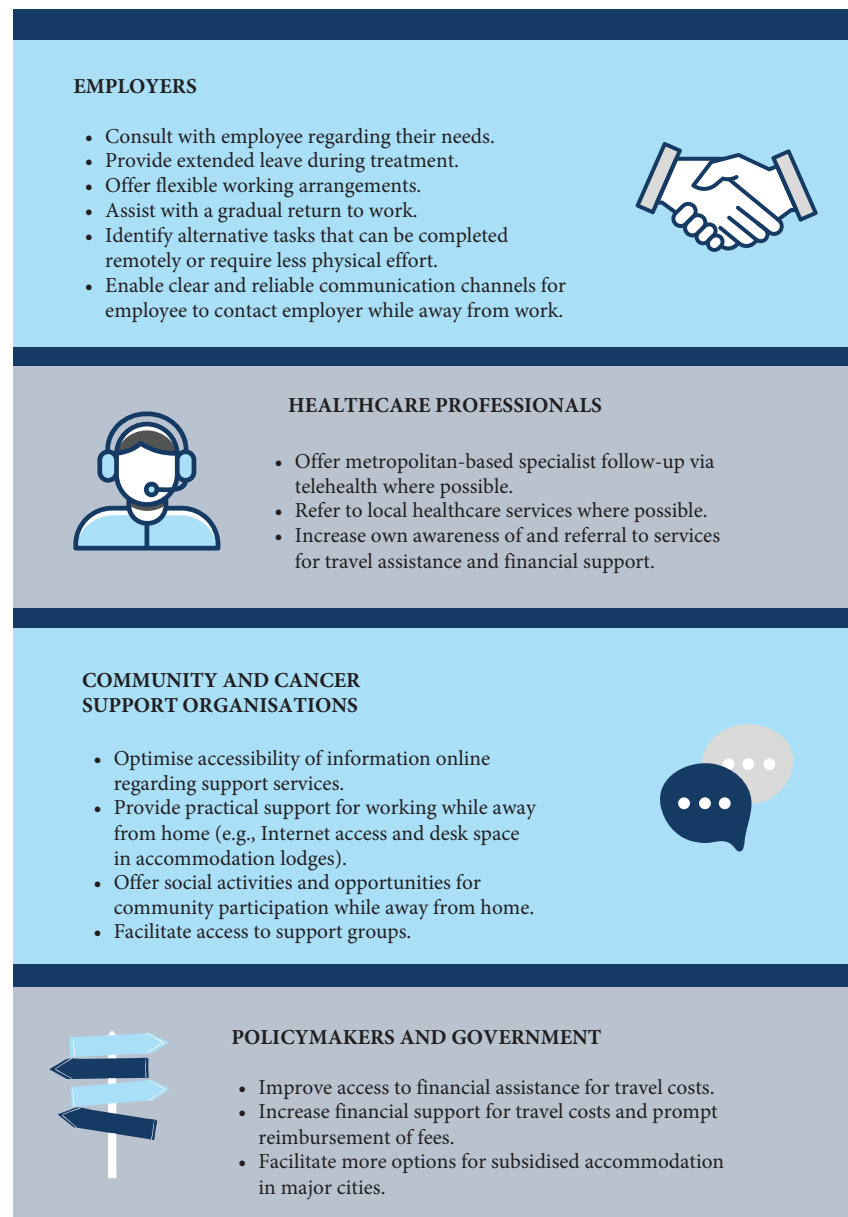


FIGURE 3: Recommendations for supporting rural cancer patients and caregivers to reduce the impact of cancer and travelling for treatment on employment.

informal care time reported in the included studies was often estimated at over \$1,000 CAD per month [30]. The scoping review also assessed work-related costs and identified that absenteeism at work (i.e., the need to take extended and often unpaid leave for caregiving) had a significant financial impact on caregivers due to loss of income and productivity at work [30]. However, presenteeism (i.e., being present at work but reduced productivity due to distress associated with the caregiving role) can have a higher economic impact than absenteeism, particularly for employers [30]. These findings highlight the benefit to employers of supporting rural caregivers, including additional paid leave or flexible work arrangements to reduce presenteeism.

In addition to supportive and adaptive workplaces, further system-level changes are needed to support rural

cancer patients and their caregivers. In our study, responses from rural caregivers identified a need to improve systems for accessing financial assistance from government sources as well as community support for returning to work. This may be particularly important for caregivers who stop work following the cancer patient's diagnosis; in the current study, one in five caregivers were no longer working following the cancer patient's diagnosis, and in 15% of the patient-caregiver dyads, neither person was employed post-diagnosis. The financial stress experienced by rural caregivers could be reduced by minimizing the costs associated with travelling for cancer treatment, for example, greater financial support for travel costs, prompt reimbursement of fees, and access to more options for subsidised accommodation in major cities. Other solutions could include

opportunities for specialist follow-up via telehealth and referral to local healthcare services where possible [11, 31, 32]. These strategies could reduce both travel costs and the time required away from work for rural cancer patients and their caregivers. Given that previous studies have identified that rural cancer patients and caregivers most commonly seek information from their general practitioners (GPs) and online sources [17, 19], efforts to improve systems for accessing financial assistance and community support should include increasing GPs' awareness of and referral to these services. Cancer support organizations may also consider optimizing the accessibility of information online regarding their support services and travel assistance.

In addition to easing financial stress, supporting rural caregivers to maintain their participation in paid employment is an important consideration for improving their health and well-being. In interviews with rural cancer caregivers, those who stopped working to care for someone with cancer reported feeling increased isolation in their caregiving role [33]. Previous studies among cancer caregivers have also found that reduced participation in paid employment due to caregiving is associated with higher symptoms of depression [34, 35]. Thus, strategies to support rural caregivers to continue in paid employment may be beneficial for their health and well-being. In our study, rural caregivers identified flexible working arrangements were important, particularly during treatment phases when the need to travel away from home was the greatest. Other strategies to support rural caregivers to maintain participation in paid employment could include providing practical support for working while away from home, such as access to the Internet and desk space in accommodation lodges and cancer treatment centres. For rural caregivers who are unable to continue in paid employment due to their caregiving responsibilities, other opportunities for social support may be important, particularly for those who have travelled away from home to accompany their loved one to a major city for cancer treatment. For example, cancer support organisations could host activities for caregivers staying at their accommodation lodges or provide information on accessing online support groups for caregivers.

Finally, supporting rural cancer patients and their caregivers to maintain participation in paid employment as able has significant implications for the economic health of rural communities and Australia more broadly. It is estimated that Australia loses \$1.7 billion in gross domestic product (GDP) every year due to reduced labour force participation among people with cancer [36]. In particular, productivity and output from rural areas are vital, with approximately two-thirds of the value of Australia's exports coming from rural areas [16]. Thus, there is an economic imperative for employers, healthcare professionals, communities, and policymakers to minimise the impact of cancer and travelling for treatment on participation in paid employment for rural cancer patients and their caregivers, in order to optimise both the health and well-being of rural cancer patients and their caregivers as well as the productivity and workforce capacity in these vital areas.

**4.1. Recommendations.** In summary, findings from this study have identified opportunities for employers, healthcare professionals, community, and policymakers to minimise the impact of travelling for treatment on employment for rural cancer patients and their caregivers (see Figure 3). Employers could provide support for extended leave, flexible working arrangements, and alternative tasks that can be completed remotely or require less physical effort. Healthcare professionals could offer follow-up via telehealth or referral to local services where possible. Cancer support organisations could optimise accessibility of information online regarding support services for travel assistance and costs and provide practical support for working while away from home (e.g., Internet access and desk space in accommodation lodges). Finally, policymakers and government could increase financial support available for travel costs, provide prompt reimbursement of fees, and more options for subsidised accommodation in major cities.

**4.2. Limitations.** This study included a large sample of rural cancer patients with a diverse range of cancer diagnoses and time since diagnosis and a substantial proportion of their caregivers. It is important to note that this study only represents rural cancer patients and their caregivers who stay at CCQ's lodges; compared to the broader population of rural cancer patients and their caregivers, participants in this study may have been more likely to access cancer-related support as they were recruited through subsidised accommodation lodges. Nonetheless, participants in this study reported limited access to work-related financial and practical support, highlighting that the need for support among rural cancer patients and their caregivers may be greater than reported here. Further research is needed to comprehensively map the employment-related needs and experiences of rural cancer patients and their caregivers. Other factors affecting the degree of employment disruption could be investigated, including length and extent of treatment and life or career stage at diagnosis, as well as the experiences of rural families with a child diagnosed with cancer. Future research could also follow-up with rural cancer patients and their caregivers over a longer period of time to investigate the long-term effects of disruption to employment following a cancer diagnosis, including whether it leads to early retirement from work for rural cancer patients and their caregivers.

## 5. Conclusions

This study found that for those living in rural areas who must travel to a major city to receive cancer treatment, disruptions to employment were common following a cancer diagnosis. Rural cancer patients commonly reported a change to employment postdiagnosis, with many no longer working due to the need to travel away from home for treatment and the impact of cancer and its treatment on their physical health. Many caregivers continued in paid employment postdiagnosis but had reduced hours, taken leave, or changed role. This study adds to previous research by

identifying opportunities for intervention at various levels, including from employers, healthcare professionals, community, and policymakers, to minimise the impact of travelling for treatment on employment for rural cancer patients and their caregivers.

## Data Availability

The datasets generated and/or analysed during the current study are not publicly available because they constitute an excerpt of research in progress but are available from the corresponding author on reasonable request.

## Ethical Approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Human Research Ethics Committee of the University of Southern Queensland (ethics approval number: ref. H17REA152).

## Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

## Authors' Contributions

BG, JA, SC, JD, MI, LZ, and AS contributed to the study conception and design. EJ, BG, LZ, and AS designed this analysis. EJ and NC completed data analysis and wrote the first draft of the manuscript. All authors commented on previous versions of the manuscript and have read and approved the final manuscript.

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## Supplementary Materials

Supplementary Figure 1: flowchart showing recruitment of participants to a longitudinal study of cancer patients and their caregivers travelling for treatment and those included in this analysis of changes to employment. Supplementary Table 1: comparison of rural cancer patients included in this analysis with those excluded due to missing employment data. Supplementary Table 2: comparison of rural caregivers included in this analysis with those excluded due to missing employment data. Supplementary Table 3: comparing characteristics of rural cancer patients employed prediagnosis by changes to work postdiagnosis ( $n = 308$ ).

Supplementary Table 4: comparing characteristics of rural cancer patients employed prediagnosis by work cessation postdiagnosis ( $n = 308$ ). Supplementary Table 5: comparing characteristics of rural caregivers employed prediagnosis by changes to work postdiagnosis ( $n = 102$ ). Supplementary Table 6: comparing characteristics of rural caregivers employed prediagnosis by work cessation postdiagnosis ( $n = 102$ ). (*Supplementary Materials*)

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