


ORIGINAL ARTICLE

Post-acute health care needs of people with head and neck cancer: Mapping health care services, experiences, and the impact of rurality

Jasmine Foley Bsc, MSpPathSt¹  | Clare L. Burns BSpPath, PhD^{1,2} | Elizabeth C. Ward BSpThy(Hons), Grad Cert Ed., PhD, FSPAA^{1,3} | Rebecca L. Nund BSpPath(Hons), GCHEd, PhD¹ | Laurelie R. Wishart BSpPath(Hons), PhD^{1,3,4} | Lizbeth M. Kenny MBBS, FRANZCR, FACR (hon), FBIR (hon), FRCR (hon), FCIRSE^{2,5} | Maurice Stevens MBBS, FRACS (ORL)²

¹School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Queensland

²The Royal Brisbane and Women's Hospital, Metro North Hospital and Health Service, Queensland Health, Brisbane, Queensland, Australia

³Centre of Functioning and Health Research, Metro South Hospital and Health Service, Brisbane, Queensland, Australia

⁴Division of Cancer Services, Princess Alexandra Hospital, Metro South Hospital and Health Service, Queensland Health, Brisbane, Queensland, Australia

⁵School of Medicine, The University of Queensland, Brisbane, Queensland, Australia

Correspondence

Jasmine Foley, Centre of Functioning and Health Research, Metro South Hospital and Health Service, Brisbane, Queensland, Australia.
Email: jasmine.foley@uqconnect.edu.au

Funding information

This research was supported by an Australian Government Research Training Program (RTP) Scholarship awarded to Jasmine Foley as part of a University of Queensland doctoral program.

Section Editor: Benjamin Judson

Abstract

Background: People with head and neck cancer (HNC) have complex health care needs; however, limited evidence exists regarding the nature or patterns of service access and use. This study explored the post-discharge health care needs and experiences of individuals with HNC from metropolitan and rural areas.

Methods: Health care appointments and services accessed by people with HNC were collated for 6-month post-treatment. Data analysis of the whole cohort examined patterns of access while journey mapping integrated participants' experiences of recovery.

Results: The 6-month service access journey was mapped for 11 people. Rural participants attended a significantly greater number of appointments ($p = 0.012$), higher canceled/missed appointments ($p = 0.013$), and saw more professionals ($p = 0.007$). Rural participants reported higher stress and burden due to service access barriers and unmet needs.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Head & Neck* published by Wiley Periodicals LLC.

Conclusions: Multiple challenges and inequities exist for rural people with HNC. Findings inform opportunities to enhance the post-treatment recovery of people with HNC in rural areas.

KEYWORDS

allied health, cancer recovery, head and neck cancer, journey mapping, rural health, service access and delivery

1 | INTRODUCTION

For individuals with head and neck cancer (HNC), the recovery journey is often long and complex due to high rates of treatment-related toxicities and significant post-treatment functional changes. Importantly, many side effects and toxicities peak in the final weeks of treatment and can persist for months, and sometimes years, after the completion of active therapy,^{1,2} making ongoing supportive care and monitoring critical in the post-treatment phase.³ As such, best practice care pathways and clinical guidelines for HNC care emphasize the need for experienced, coordinated, and comprehensive multidisciplinary team (MDT) health care supports that extend well into the post-acute phase of care.⁴⁻⁸

The need for holistic, long-term MDT care of individuals with cancer is not a new concept and was highlighted almost 15 years ago in the seminal report *From cancer patient to cancer survivor: lost in translation*.³ For people with HNC, this support involves ongoing monitoring by medical specialists, but also input from a wide range of nursing and allied health professionals who facilitate recovery and maximize survivorship. Importantly, the practical and personal implications of coordinating and implementing care plans with this degree of complexity are not known. Indeed, the nature of post-acute care pathways has been poorly reported in the current literature,⁵ with most attention focusing only on specialist medical surveillance for disease recurrence.⁹⁻¹¹

Furthermore, as HNC MDT clinics are typically located within large metropolitan hospitals, it is to be expected that individuals from rural areas may face additional challenges in accessing and coordinating these complex post-acute care plans. While the rural disadvantage is well documented,¹²⁻¹⁶ there remains inadequate literature on the recovery needs of those individuals with HNC living in rural areas. This information is necessary to allow health services not only to recognize the nature of the issues that exist for these patients, but more importantly to identify ways to inform change.

While rurality in itself does not appear to influence the type and appropriateness of active care and treatment

options available for people with HNC,^{17,18} there is evidence that inequities exist at the peripheries of the care continuum. Prior to primary treatment, there are recognized inequities for people from rural areas associated with delays in referral, diagnosis and/or treatment commencement.^{18,19} These factors are known to contribute toward higher risk of death at 3-year follow-up.²⁰ Rurality and distance from treating center has also been reported as a risk factor for unplanned hospital readmissions²¹ and 30-day emergency department use²² following active treatment completion, with the patient commonly presenting to an emergency department at a different hospital to where they received primary care. Thus, while receiving care locally is desired, the issue of care fragmentation is real for these individuals and is unfortunately associated with higher risk of complications including death.^{23,24}

Given the complex care requirements, it is not surprising that studies suggest up to 60% of people with HNC have unmet care needs.^{25,26} While accessing services closer to home was reported as one of these needs, at present there is little understanding of exactly what these access issues are, and to what extent care needs are “unmet” due to geographical remoteness. Having a better understanding of the post-acute care needs for people with HNC is necessary for regional and rural health services to plan and equip themselves better to manage this population. As there is currently no published literature on how patients engage with multidisciplinary services in the post-acute phase of the HNC care, nor how this may be impacted by geographical remoteness, the aim of this study was to map the multidisciplinary post-acute health care service access, utilization, needs, and experiences of people with HNC from metropolitan and regional/remote areas and examine if differences exist by rurality.

2 | METHODS

2.1 | Design

This was a prospective mixed-methods longitudinal cohort study designed to understand the patient journey regarding service utilization, needs, and experiences of

people with HNC during the initial 6-months following completion of curative treatment. Institutional ethics approval was obtained prior to study commencement and all participants provided informed written consent to participate.

2.2 | Participants

Eligible participants were all adults presenting with a primary diagnosis of HNC of the lips, oral cavity, oropharynx, pharynx, hypopharynx or larynx, receiving curative-intent treatment through the cancer care services at the participating quaternary hospital facility in Queensland, Australia, between March 2019 and January 2020. Only participants who completed all primary care through this hospital were eligible. This study was conducted within state-wide publicly funded health service where there is no fee to access inpatient/outpatient cancer services, and access to care is not influenced by health insurance status. Additionally, subsidies for travel and accommodation are available to reduce financial barriers to accessing care.

Those with a primary tumor of the skin, nasopharynx, or salivary gland and those who received palliative care or anyone presenting with a cancer recurrence were excluded. Participants were recruited initially into two categories based on remoteness of residence: (1) metropolitan and (2) non-metropolitan, which is hereon referred to as rural (regional and remote areas). The Australian Statistical Geography Standard (ASGS) Remoteness Structure²⁷ was used to classify people by remoteness category into either metropolitan or non-metropolitan. This system categorizes remoteness by relative access to services (such as health care, education, transport, and social services) as opposed to population density alone. This system of classification was designed to allow more accurate comparisons across geographical populations for the purposes of statistical analysis, reporting and research. Metropolitan areas have no restrictions on access to all necessary services whereas non-metropolitan have reduced or limited access to all or some services. Once participants were categorized by remoteness, maximum variation sampling was utilized to ensure the recruited sample of participants represented the spectrum of perspectives that could be expected within the larger population (including typical and deviant cases).²⁸ Maximum variation sampling parameters applied were: tumor staging (Stages 1,2 vs. 3,4), tumor location, surgical versus non-surgical treatment, working versus retired/non-employed, patients with and without dependent children, and patients with and without a spouse/carer.

It is noted that recruitment for this project was impacted by the COVID-19 pandemic. As COVID-19

caused interruptions to, and changes in, the delivery and/or access to outpatient care at many hospital and health care facilities across Queensland, the original recruitment window was reduced to only those participants able to be recruited at MDT presentation between March 2019 and July 2019. This recruitment window allowed participants time to complete active treatment and 6-months of post-acute data collection prior to the onset of COVID-19 service disruptions.

2.3 | Data collection

Three methods of data collection were used to gather the information required to map the participants' post-acute health care journeys. Firstly, the health service's electronic records and appointment booking systems were accessed to collect participant information including: demographics, medical diagnosis, cancer treatment modality, date of completion of curative treatment, appointments attended (in-person, telehealth or telephone), and outcome of appointment (booked, attended, failed to attend, and canceled) relating to HNC care. Secondly, participants utilized a diary to document appointments not captured by the electronic systems, such as appointments provided by other public or private health providers. For each appointment, the clinical need, location, the attending professionals, and whether the appointment was pre-scheduled or required due to change in condition/function were recorded. Only appointments directly or indirectly relevant to, or impacted by, their cancer care were included in this study and pre-existing or unrelated appointments were not recorded. The diary was completed in hardcopy or electronically depending on participant preference. Thirdly, each month over the 6-month period, participants completed a phone interview with a member of the research team. The purpose of the interview was twofold: (1) to discuss attendance at appointments and check this against the cancer center's records and participant's diary entries to ensure documentation was accurate and (2) explore participant's experiences of accessing these services and ongoing care needs. A semi-structured interview guide was utilized to ensure consistency (Table S1). All phone calls were recorded for analysis and used to create the individual participant narratives of experience.

2.4 | Data analyses

Data analysis involved two related but separate processes. In the first analysis stage, summary statistics regarding the services accessed by the full cohort was analyzed, including number of appointments, type of appointment

(phone, telehealth, or in-person), professional providing care, location of care, reason for appointment, and whether appointment was pre-planned or needed due to change in condition/function. Quantitative data reporting on service metrics and participant travel were analyzed using descriptive statistics (median, mean, and range), and statistical significance was calculated using the non-parametric Mann-Whitney two-tailed *U*-test. This test is reliable to use in small sample sizes.²⁹ Distances and times traveled to appointments were calculated from participant residence postcode to appointment location each way using Google maps³⁰ via road or public transport as applicable, with flight times retrieved from airline online records. These distances and travel times were verified with the participants. The use of multiple data sources (electronic booking systems, electronic medical records, health diary, and phone interviews) used in this study allowed for the triangulation of results and cross-checking of information through an iterative process that enabled verification of information.

In the second stage of data analysis, journey mapping was used to visualize the services accessed and recovery pathways with a comparison by remoteness. Journey mapping is a novel methodology that incorporates and presents multiple sources of information to illustrate a complex health care process experienced by an individual.^{31,32} Journey mapping uses consecutive contacts between services and patients, known as “touch points,” along with the emotional experience, motivations, and attitudes expressed throughout the cumulative episodes of care.³² This produces insights into the individual experiences of patients by telling their story in a concise and visually compelling way, thereby promoting emotional engagement with the reader.³² Previous use of journey mapping in the evaluation of rural renal health care found the process beneficial for structuring and organizing case study data when planning the transfer of care from a metropolitan facility to local services.³³

In this study, we adapted and modified a longitudinal patient journey map published by Meyer³⁴ as this framework allowed for the presentation of a large number of separate touch points. Details of each appointment were recorded as a separate touch point and listed consecutively by date. As not all participants provided specific dates for private appointments attended (e.g., general practitioners), these episodes were recorded on the journey maps without a specific date. Participants' perceptions and experiences of services were documented in narrative form as undertaken and reported by Kelly, Wilden, Herman, Martin, Russell, Brown³³ and key quotes were extracted for inclusion in the journey maps.

3 | RESULTS

There were 23 participants who met both the study eligibility criteria and the modified COVID-19 recruitment timeframe. However, 12 were subsequently removed as they were either lost to follow-up ($n = 6$), requested to be removed from the study post-treatment ($n = 4$), or experienced cognitive decline/delirium which impacted data collection ($n = 2$). Of those who were lost to follow up or asked to be removed from the study, the demographics of age (mean 64 years), sex (70% male) and spouse/carer (80%) were similar to the final cohort; however, slightly more (70%) were from metropolitan areas. Complete data sets were analyzed for 11 participants, including five from metropolitan and six from rural locations. Most participants were male (72.7%), an average age of 62 years, had primary oropharyngeal tumor (63.6%), Stages 3–4 disease (54.5%) and nodal stage N0-1 (72.7%) (Table 1). Just over half underwent chemoradiotherapy (54.5%), fewer underwent surgery with post-operative radiotherapy (36.4%), and radiotherapy only (9.1%). A prophylactic percutaneous endoscopic gastrostomy (PEG) was placed in 36.4% of participants. Most participants had a spouse/carer living with them at the time of diagnosis (90.9%) and did not have dependent children (81.8%). Just over half of the cohort were not employed or retired at time of diagnosis (54.5%). All maximum variation parameters were achieved within the total cohort of 11; however, when exploring the distributions within the metropolitan and rural subgroups, the metropolitan cohort did not have any participants who were female, pharyngeal primary site, N2-3 staging, or with spouse/carers, while the rural cohort did not have participants who had a laryngeal primary site or treated only with radiotherapy (Table 1).

3.1 | Part 1: Post-acute services accessed by people with head and neck cancer

3.1.1 | Appointments attended and canceled

Number of appointments, professionals, and sites attended are shown in Table 2. Compared with the metropolitan cohort, rural participants attended significantly ($z = 2.487$, $p = 0.012$) more health care appointments (Mdn = 44, range 32–96) and experienced significantly ($z = 2.12$, $p = 0.03$) more missed or canceled appointments (Mdn = 5, range 2–12). The combined cohort percentage of missed or canceled appointments for all bookings was 10.6%. Missed or canceled HNC specialists' appointments between rural and metropolitan participants were not

TABLE 1 Whole cohort demographics and characteristics

		No. participants in total cohort		
		Subgroup analysis		
		No. of metropolitan participants	No. of rural participants	
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Demographics and characteristics		11 (100)	5 (45.5)	6 (54.5)
Age group	0–64	7 (63.6)	2 (40)	4 (66.7)
	65 & older	4 (36.4)	3 (60)	2 (33.3)
Sex	Male	8 (72.7)	5 (100)	3 (50)
	Female	3 (27.3)	0 (0)	3 (50)
Primary site	Oropharyngeal	7 (63.6)	3 (60)	4 (66.7)
	Pharyngeal	2 (18.2)	0 (0)	2 (33.3)
	Laryngeal	2 (18.2)	2 (40)	0 (0)
T-classification	T1-2	5 (45.5)	3 (60)	2 (33.3)
	T3-4	6 (54.5)	2 (40)	4 (66.7)
N-classification	N0-1	8 (72.7)	5 (100)	3 (50)
	N2-3	3 (27.3)	0 (0)	3 (50)
Treatment group	Surgery + PORT	4 (36.4)	1 (20)	3 (50)
	Combined CXRT	6 (54.5)	3 (60)	3 (50)
	XRT only	1 (9.1)	1 (20)	0 (0)
Prophylactic PEG	Yes	4 (36.4)	1 (20)	3 (50)
	No	7 (63.6)	4 (80)	3 (50)
Employment status	Employed/own business	5 (45.5)	3 (60)	2 (33.3)
	Not employed/retired	6 (54.5)	2 (40)	4 (66.7)
Support	Spouse or carer	10 (90.9)	5 (100)	5 (83.3)
	No spouse or carer	1 (9.1)	0 (0)	1 (16.7)
Dependents	Dependent Children	2 (18.2)	1 (20)	1 (16.7)
	No dependents	9 (81.8)	4 (80)	5 (83.3)

Abbreviations: CXRT, chemoradiotherapy; PORT, postoperative radiotherapy; XRT, radiotherapy.

significant ($z = 0.409$, $p = 0.68$) although it was statistically significant for appointments with other professionals ($z = 2.031$, $p = 0.042$). The number of HNC specialists' appointments accessed by the rural and metropolitan groups was not significant ($z = 0.8292$, $p = 0.407$). Two rural participants experienced conflicting or overlapping bookings at the local, regional, or metropolitan hospitals which resulted in missed appointments. Rural participants were required to travel to 2–3 hospital facilities to attend appointments, while the metropolitan participants only accessed care at the treating cancer facility.

3.1.2 | Professionals providing care

Rural participants interacted with a significantly ($z = 2.659$, $p = 0.007$) higher number of health professionals (Mdn = 17; range 10–18) and accessed significantly ($z = 2.625$, $p = 0.008$) more nursing/allied health professionals (rural Mdn = 36, metro Mdn = 16) compared to metropolitan counterparts (Mdn = 7; range 5–9) (Table 2). Across the whole cohort, 21 different health professions providing HNC post-treatment care were accessed, with rural participants requiring support from nearly double

TABLE 2 Services accessed by all participants during 6-month post-acute recovery period

	Number of attended appointments ^a	No. of appointments attended for HNC specialists, <i>n</i> (%)	No. of appointments attended for non-HNC specialists, <i>n</i> (%)	No. of all FTA & canceled appointments ^a	No. of canceled and FTA for HNC specialists only	No. of canceled and FTA for non-HNC specialists	No. of hospital sites accessed	Total number of professionals accessed ^a
Rural participants								
Regional 1	57	6 (10.5)	51 (89.5)	5	0	5	3	18
Regional 2	32	6 (18.75)	26 (81.25)	5	1	4	3	17
Regional 3	32	3 (9.3)	29 (90.7)	3	0	3	2	17
Remote 4	52	9 (17.3)	43 (82.7)	12	0	12	3	14
Remote 5	96	7 (7.2)	89 (92.7)	12	5	7	3	18
Remote 6	36	16 (44.4)	20 (55.5)	2	1	1	2	10
<i>Median</i>	44	6.5	36	5	0.5	4.5	3	17
Metropolitan participants								
Metro 1	21	5 (23.8)	16 (76.2)	4	1	3	1	9
Metro 2	32	8 (25)	24 (75)	1	0	1	1	8
Metro 3	17	7 (41.2)	10 (58.8)	2	1	1	1	6
Metro 4	9	5 (55.5)	4 (44.5)	0	0	0	1	5
Metro 5	20	3 (15)	17 (85)	2	0	2	1	7
<i>Median</i>	20	5	16	2	0	1	1	7

Note: HNC specialists = Ear nose and throat, plastics and reconstructive surgery, maxillofacial surgery, radiation oncology, medical oncology.

Abbreviations: FTA, failed to attend; HNC, head and neck cancer.

^aFor all professionals.

those accessed by the metropolitan participants (Table 3). Medical services included otolaryngologists, maxillofacial specialists, plastics and reconstructive surgeons, medical oncologists, radiation oncologists, general practitioners, gastroenterologists, neurologists, radiology, and emergency physicians. Allied health and other support services accessed included speech pathology, nutrition and dietetics,

physiotherapy, occupational therapy, social work, psychology, dentistry, nursing, and cancer care coordinators. An additional 10 professions were indirectly needed during recovery. For example, to biopsy bowel lesions noted incidentally during HNC diagnostic work up or for urology review secondary to complications from being unable to swallow medications.

TABLE 3 Health care professionals accessed during recovery

	Rural participants	Metropolitan participants	
Directly needed for head and neck cancer recovery	Radiation	Radiation	
	Oncologist	Oncologist	
	Medical	Medical	
	Oncologist	Oncologist	
	Ear, Nose and Throat surgeon	Ear, Nose, and Throat specialist	
	Gastroenterology	Gastroenterology	
	Neurology	Neurology	
	Radiology	Radiology	
	General Practitioner	General Practitioner	
	Maxillofacial Surgery	Cancer Care Services	
	Plastics and Reconstructive Surgeon	Speech Pathology	
	Dental	Dietetics	
	Speech Pathology	Psychology	
	Dietetics		
	Psychology		
	Social Work		
	Physiotherapy		
	Occupational Therapy		
	Cancer Care Services		
	Nursing		
	Wound Clinic		
	Emergency Department		
	Hospital Avoidance Program		
	Indirectly needed for head and neck cancer recovery	Endocrinology	Endocrinology
		Urology	Urology
Respiratory Specialists			
Anesthetics			
Infectious Diseases			
General Surgeon			
Immunology			
Cardiology			
Cardiac Rehabilitation			
Thoracic Specialist			

3.1.3 | Unmet care needs

Just over half ($n = 4$) of the rural participants identified that they had unmet support needs locally. This included local access to dental services, audiology, speech pathology, and support for fatigue management. Two participants stated they needed welfare and financial support due to costs associated with their treatment and travel. For example, one participant had waited 8-weeks for reimbursement of travel costs.

3.1.4 | Travel to access care

Participant travel associated with attending appointments is summarized in Table 4. Metropolitan participants used one to two forms of transport to travel to appointments, including public transport. Most rural participants traveled to the cancer center or their nearest regional hospital by car. However, two rural participants utilized three forms of transport, needing to drive to their nearest regional town, then fly to the metropolitan city, and self-fund taxi transfers to the cancer center. All rural participants reported that they required a support person to drive to appointments due to poor health. One remote participant who did not have a support person required a health professional from the local service (i.e., social worker or nurse) to accompany them. In total, rural participants spent a median of 26 h 25 min traveling to appointments, compared with only 8½ h for metropolitan participants.

3.2 | Part 2: Mapping patients' journeys—A regional and metropolitan experience

The following two case studies utilize patient journey mapping—one from a regional participant and one from a metropolitan participant, to illustrate the services accessed and experience across the recovery phase. These two cases were chosen as they satisfied the majority of the maximum variation sampling requirements and represented characteristics close to the average regarding

TABLE 4 Traveling mode and times

	Mode of transport	Travel time to regional appointments return per trip	Total travel time to metro appointments return per trip	Total travel time for all appointments
Rural participants				
Regional 1	Private car	2 h 20 min	4 h	27 h
Regional 2	Private car	5 h	7 h 20 min	31 h
Regional 3	Private car	Not accessed	6 h 40 min	24 h
Remote 4	Private car, plane, and taxi	1 h 20 min	4 h 30 min (car + flight)	21 h
Remote 5	Private car, plane, and taxi	1 h 20 min	3 h 40 min (car + flight)	25 h 50 min
Remote 6	Private car	Not accessed	8 h 30 min	33 h 20 min
<i>Median</i>		1 h 50 min	6 h 40 min	26 h 25 min
Metropolitan participants				
Metro 1	Bus, train, and bus	n/a	2 h 30 min	55 h
Metro 2	Bus	n/a	0 h 30 min	8 h 30 min
Metro 3	Private car	n/a	0 h 15 min	4 h 30 min
Metro 4	Private car and bus	n/a	1 h	7 h
Metro 5	Private car	n/a	0 h 45 min	21 h
<i>Median</i>			0 h 45 min	8 h 30 min

Note: Traveling time excludes any time waiting for transport (e.g. in airport), staying overnight or waiting to attend appointments and is only calculated for average times spent in a vehicle or plane.

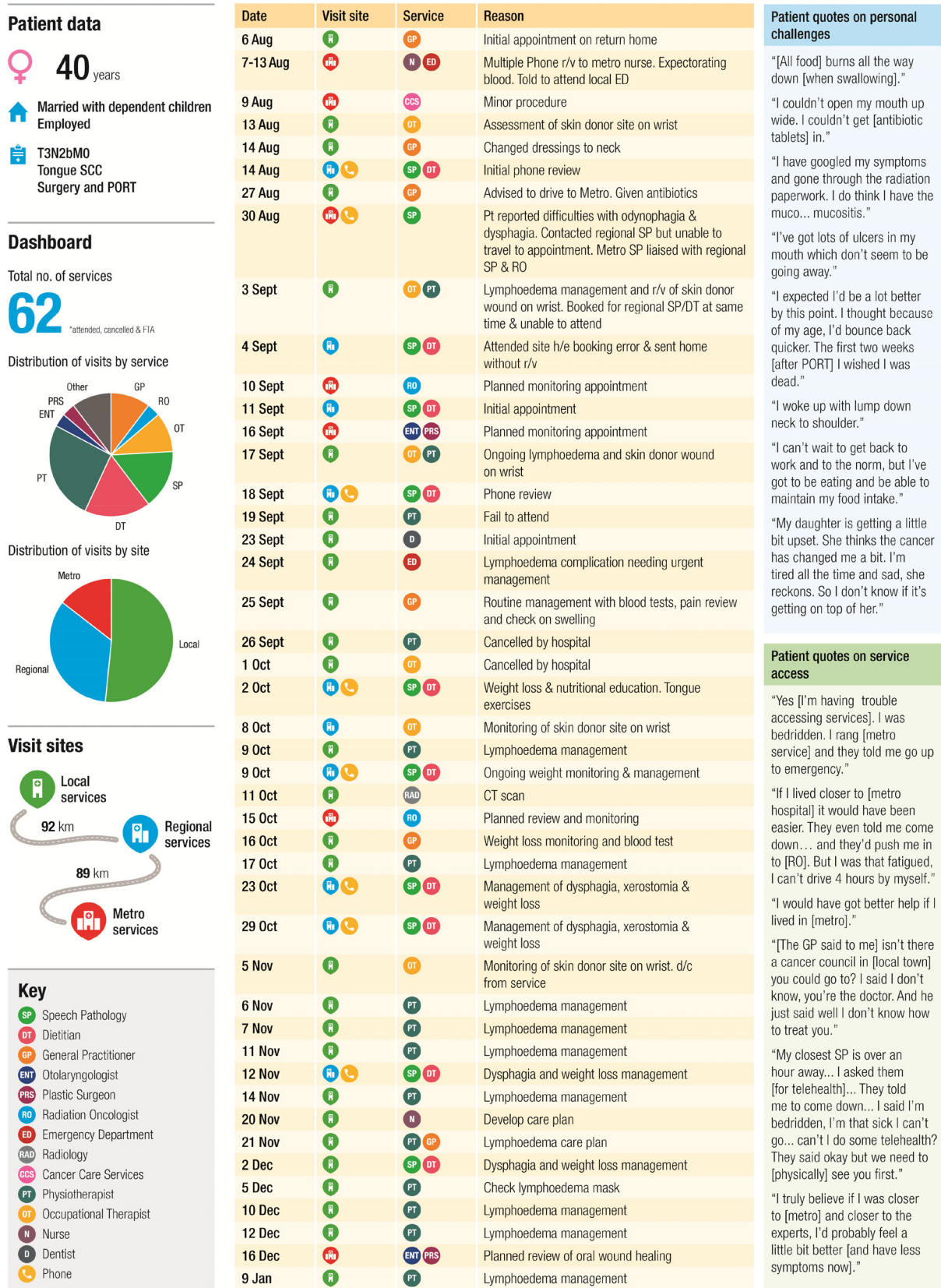
number of appointments and services accessed (i.e., they do not represent outlier cases). Figures 1 and 2 represent the journey maps for each case study respectively, and Figure 3 compares the number and distribution of professionals accessed.

3.2.1 | Case study 1: A regional experience

Patient 1 is a 40-year-old-female diagnosed with T3N2bM0 squamous cell carcinoma (SCC) of the tongue (Figure 1). She was treated with surgery and postoperative radiotherapy. She is married, working full time and has two dependent school-aged children. Her husband traveled away for work for weeks at a time. She lived in an outer-regional town with a nearby small local hospital. The closest regional hospital was 2½ h return drive (92 km) from home and the metropolitan hospital was 4 h return drive (180 km). Patient 1's journey was typical among the rural study participants, with her accessing a total of 57 appointments (cohort median was 50),

experiencing five missed/canceled appointments and seeing 18 different professionals who were located across local, regional, and metropolitan facilities (Figure 3).

Patient 1 reported physical barriers of illness and travel distances as challenges in accessing services and meeting her care needs. She experienced ongoing side effects after returning home that she was not wholly prepared for "I expected I'd be a lot better by this point. I thought because of my age, I'd bounce back quicker." The side-effects she experienced included dysphagia, odynophagia, mucositis, xerostomia, lymphedema, fatigue, weight loss, and respiratory infections. Due to these side effects, she did not feel capable to drive herself to appointments and sought as much help locally as possible. Her local facility had limited experience managing HNC, hence travel to regional and metropolitan facilities was needed for many appointments. On some occasions, she was physically too unwell to travel, "I was bedridden." With her husband away, she relied on family or friends who took time off work to take her to the hospital and/or to pick her children up from school while she attended

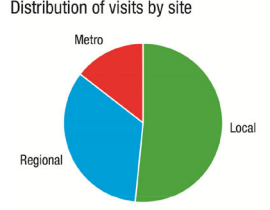
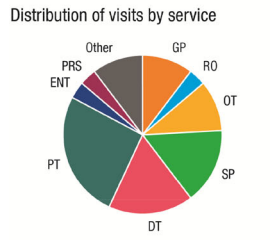


Dashboard

Total no. of services

62

*attended, cancelled & FIA



Key

- Speech Pathology
- Dietitian
- General Practitioner
- Otolaryngologist
- Plastic Surgeon
- Radiation Oncologist
- Emergency Department
- Radiology
- Cancer Care Services
- Physiotherapist
- Occupational Therapist
- Nurse
- Dentist
- Phone

FIGURE 1 Patient 1 journey map of 6-month post-acute recovery phase: A regional experience. CT scan, computed tomography scan; d/c, discharge; ED, emergency department; FTA, failed to attend; PORT, postoperative radiotherapy; SCC, squamous cell carcinoma [Color figure can be viewed at wileyonlinelibrary.com]

Patient data

♂ 74 years

🏠 Retired with a spouse
No dependent children

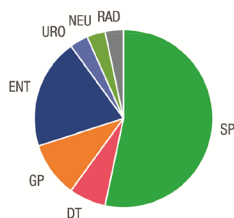
📄 T3N1M0 SCC Larynx
Laryngectomy with voice prosthesis
PORT

Dashboard

Total no. of services

33 *attended, cancelled & FTA

Distribution of visits by service



Visit sites



Key

- SP Speech Pathology
- DT Dietitian
- GP General Practitioner
- ENT Otolaryngologist
- RO Radiation Oncologist
- RAD Radiology
- NEU Neurologist
- URO Urologist
- ☎ Phone

Date	Service	Reason
23 Sep	SP DT RO	Initial appointments post treatment completion
30 Sep	SP	Review voice prosthesis & swallowing management. Unable to produce voice
Sep (date n.s.)	GP	General monitoring
9 Oct	SP ☎	Check stoma management
16 Oct	SP DT	Swallowing & weight monitoring. d/c DT
Oct (date n.s.)	GP	General medical review
6 Nov	SP	SP contacted CCS and ENT to request urgent review appointment
11 Nov	GP	General medical review and scripts
13 Nov	RO	Review and monitoring
13 Nov	ENT	Initial appointment post treatment. Voicing production needing medical management
18 Nov	SP ENT NEU	Botox injected by neurologist to help with voicing
26 Nov	URO	Unable to swallow medication for prostatomegaly, resulting in UTI
26 Nov	SP	Ongoing difficulty voicing. SP liaised with neurologist
4 Dec	SP ☎	Review and check progress with voicing
16 Dec	ENT NEU	Repeat botox injection
18 Dec	SP	Ongoing voicing difficulty
6 Jan	SP	Ongoing voicing difficulties. Pt distressed about difficulty with poor voice and communication difficulties
14 Jan	SP ☎	Ongoing voice difficulties. Planning for VFSS to assess voice issues
22 Jan	SP RAD	VFSS and voicing study
23 Jan	ENT	Review. Planning for additional botox injection for voicing
3 Feb	SP ☎	Scheduled phone review. Nil answer by Pt
4 Feb	SP ☎	Discussed plan for voicing and further botox injection
5 Mar	ENT SP	ENT appointment cancelled h/e communication error & Pt attended site. SP review of voice prosthesis
27 Mar	SP	Review voice prosthesis and voicing. Stomal ulcer management
27 Mar	ENT	Planned monitoring appointment

Carer quotes on service access

"He sort of fell through the cracks there for a couple of weeks [immediately post treatment]. We never saw anybody for a month... or six weeks, did we? Other than [ENT] and speech pathology."
 "No [we haven't had any trouble accessing any services needed]."
 "The girls really looked after him. The ladies at speech pathology. He's seen them regularly."
 "[ENT] check him every three months. It's a regular appointment. Then the speech pathologist organised [a VFSS] so they would have something to look... so they could have a look to see what was going on before we went to the [ENT]."

* Carer completed all phone call interviews as patient unable to speak on phone. Patient was present with carer for all phone calls.

Carer quotes on personal challenges

"Where he had the radiation, [the skin] all broke out around the throat and the stoma."
 "We're managing. If we can get [his] voice to work, that's the main thing... it's very frustrating."
 "He eats everything. Just in small portions or small pieces."
 "If there's [no voice] after the next [botox] treatment then we're going to have to look at other avenues."
 "It's six months today since the operation and it's a bit of a hard road."
 "I said to him one day, he's been a bit down, and I said to him do you want to go see someone? And he said, no, I'm right. You know he said with his sign language and his writing."
 "I think we're battling along pretty well. Not much more you can do other than that is there?"
 "[The lack of voice] is very disappointing for him... when the voice crackled on the Friday and the Saturday morning. He counted to five... and the face on him! It was just beautiful. He rang his daughter and then he rang his son... then [the voice] went."
 "When he had the scan the other day, [the SP] put me in behind a screen where I could see the scans while they were giving him the swallow test... you could see all the food, see it going down. But there's a tightness in the muscle that won't let [air] come back up [for voicing]. And they pinpointed it five or six vertebrae down. They measured it all. The head radiologist was all there... [The SP] explained it to me. It was good to see."

FIGURE 2 Patient 2 journey map of 6-month post-acute recovery phase: A metropolitan experience. d/c, discharge; FTA, failed to attend; n.s., not specified; PORT, postoperative radiotherapy; Pt, patient; SCC, squamous cell carcinoma; UTI, urinary tract infection; VFSS, videofluoroscopic swallow study [Color figure can be viewed at wileyonlinelibrary.com]

appointments. Patient 1 also felt that her appointments were not coordinated, and the different health services did not communicate efficiently and effectively, resulting in missed appointments ($n = 5$), "They rearranged my appointment and I turned up on the date I was originally supposed to turn up and they'd rescheduled it for the day before. And they couldn't see me." This put the onus on

her to liaise with and update professionals on her care needs and manage her schedule, causing additional stress and burden.

Patient 1 reported that while local health services did try to assist her, she felt that they were not always able to provide appropriate care due to a perceived lack of knowledge, expertise, and access to the services she

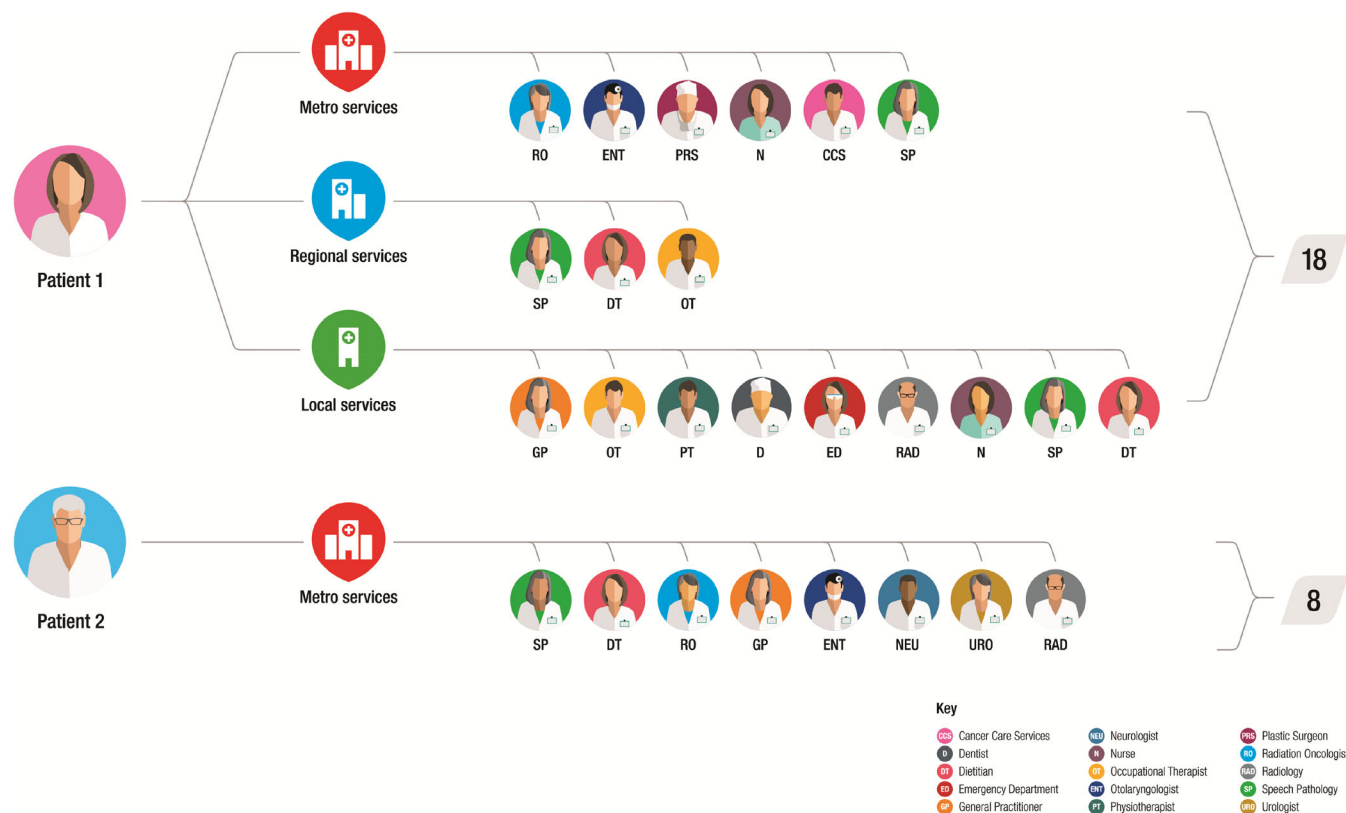


FIGURE 3 Health professionals accessed during 6-month post-acute recovery phase: Comparison of Patient 1 and Patient 2 [Color figure can be viewed at wileyonlinelibrary.com]

required “the [GP] said, I don’t know anything about radiation patients.” She reported seeing several general practitioners and local emergency department doctors who were unsure of how to manage her symptoms, with one stating “I don’t know how to treat you.” She acknowledged that HNC was not commonly dealt with by her local services and her perceived inadequacy in care was likely due to their limited HNC exposure and experience. She felt more training and contact with metropolitan HNC specialists would improve local services. Patient 1 also reported inconsistency in the services that she could access locally. She was referred to local physiotherapy and occupational therapy services promptly on return home, however, was required to travel to the regional hospital to access speech pathology and dietetics services for a large proportion of her recovery, only being referred to her local facility’s services once side effects had stabilized. When Patient 1 requested to access the regional hospital speech pathology services from home via telehealth, facility procedures required her to attend an in-person appointment first, “[I said to regional speech pathologist] I’m that sick I can’t [drive]. You’re over an hour away, can’t I do some telehealth... and they said okay we’ll do that, but we first need to see you [in person]. And that appointment isn’t until next week.”

The burden of needing to advocate for and self-manage her care was described early in Patient 1’s recovery with her completing internet searches of her symptoms and self-diagnosing oral mucositis. Patient 1 also reported contacting various staff (cancer care nurses, radiation oncologist and speech pathologists) at the metropolitan cancer center for advice and assistance and to facilitate more timely access to services at the regional hospital. She described one conversation with a metropolitan radiation oncologist regarding the re-scheduling of the regional speech pathology appointment for the following week “[the oncologist] said basically that wasn’t good enough and rang them [regional service] and I saw them the next day. They basically fast-tracked me.”

3.2.2 | Case study 2: A metropolitan experience

Patient 2 is a 74-year-old male diagnosed with T3N1M0 SCC of the larynx who underwent a total laryngectomy with post-operative radiotherapy (Figure 2). He had a supportive, engaged wife who attended all appointments and completed the study phone-calls on his behalf due to communication difficulties. Both were retired and lived

close to the metropolitan cancer center. Patient 2 experienced one of the more complicated recovery journeys among the metropolitan group “It’s six months today since the operation and it’s a bit of a hard road.” He accessed a total of 33 appointments (metropolitan cohort median was 22) from eight different health professionals (Figure 3). All services needed for his HNC recovery were provided at the cancer center where he received active treatment, with the exception of his GP appointments.

At the completion of treatment, Patient 2 experienced skin breakdown “Where he had the radiation, it all broke out around the throat and the stoma.” His wife described feeling as though “[he] fell through the cracks” during the initial 6-week post-treatment as they did not see the radiation oncology specialist during this time, although no appointments with the radiation oncologist were scheduled or canceled during this period. Patient 2 did however have regular contact with speech pathology and dietetics services during this time.

Patient 2’s biggest recovery concern centered on his communication rehabilitation. A voice prosthesis was placed at time of surgery to facilitate voice production; however, due to physical/structural issues impacting respiratory airflow, Patient 2 was unable to achieve voice postoperatively. This necessitated multiple appointments with the speech pathologist, otolaryngologist, and referral to a specialist neurologist for Botox injections. The inability to use this voice was a major source of distress “he’s been a bit down, and I said to him do you want to go see someone? And he said, no, I’m right. You know he said with his sign language and his writing.”

While his voice rehabilitation was protracted and complex, he expressed no difficulties in gaining access to knowledgeable staff, no concerns with physically accessing the hospital, and reported no need for self-advocacy. Indeed, his reports of services indicated that the metropolitan service providers actively engaged him/his wife in his care “When he had the scan the other day, [the speech pathologist] put me in behind a screen where I could see the scans while they were giving him the swallow test... you could see all the food, see it going down.... [The speech pathologist] explained it to me. It was good to see.” Staff also coordinated many appointments on his behalf and liaised directly with other professionals so that he did not have to. Patient 2 and his wife did not believe there were any areas of service access and delivery that could be improved upon or needed to be changed.

4 | DISCUSSION

Mapping the post-acute health care needs for people with HNC has captured unique insights into the complexity of

the recovery process and has importantly highlighted the inequity in access to health care services for rural people. This inequity resulted in a greater recovery burden for rural people as illustrated by a higher utilization of appointments, more missed or canceled appointments, accessing more hospital facilities, and needing to access services from a greater number and array of professionals. Ultimately, this culminated in additional stress for people from rural areas compared with their metropolitan counterparts, as illustrated by the case study experiences depicted in the journey maps.

Follow-up and surveillance of people who have undergone HNC treatment is a well-established need, with the majority of cancer services using protocols to guide this process.³⁵ While there is no international consensus on the frequency of follow-up appointments,^{10,36} many protocols advocate for reviews to be scheduled as much as monthly, and up to third monthly, in the first year.⁹ Even the most proactive of these protocols would not account for the high levels of service utilization observed in this study during the first 6 months of follow-up care. This is especially so for the rural participants who required nearly double the number of services compared to the metropolitan cohort. An important observation is the division of service utilization between HNC medical specialists and professionals who provide other critical aspects of post-acute support such as allied health, dentistry, and clinical nurse specialists. The abovementioned protocols report heavily, or solely, on care by HNC specialists who represented only a small proportion of the total number of appointments accessed in this study. Rather, our findings highlight that allied health and nursing comprised the majority of appointments sought in the recovery phase of care.

While the inclusion of allied health and clinical nurse specialists is standard practice in most multidisciplinary HNC teams, how these services should be coordinated is poorly reflected in many post-treatment protocols.^{37,38} Indeed, much of the literature published on this area focuses on specialist medical follow-up aimed primarily at the detection of recurrences or spread of disease.^{10,35,39} In contrast, the focus of allied health and nursing professionals in the follow-up period is on quality of life and symptom management.³⁸ However, these services are usually booked on an ad-hoc basis,^{37,38} which puts the onus on medical staff to identify the need for and refer to these services or patients to self-advocate for assistance. In facilities with MDT clinics where staff are familiar with the needs of people with HNC, this is likely not a problem. However, for providers who infrequently manage people with HNC, like rural services, it is difficult to pre-empt and plan what is needed without adequate representation of allied health and supportive services in the literature or post-acute surveillance protocols.

Another interesting finding to come from this work was the number of canceled and missed appointments, which occurred in 10.6% of all bookings. This is lower than the 20% rate observed in one study reporting on missed follow-up appointments for people with HNC in the United Kingdom³⁶; however, that study reported on HNC clinic attendance and did not delineate by rurality or whether the appointments were solely for medical specialists or incorporated other professionals. In our study, non-HNC specialist professionals like allied health, especially those from rural areas, were significantly more likely to have missed or canceled appointments. Some of these missed appointments were caused by overlapping and conflicting bookings between the different hospital sites, highlighting issues of poor communication between services. Improving communication and coordination between services is critical in delivering optimal health care^{40–42} and the need to address this between specialist cancer services and local, primary care providers has been highlighted as a key requirement in cancer recovery.³ This need for integrated and coordinated health networks is not a new concept in cancer care^{5,8,43,44} and is also recognized as necessary to minimize delays and difficulties in transferring care, as was observed to occur in this study. Delayed, missed, and overlapping appointments, primarily in rural allied health, are critical to understand and address in order to ensure that people with HNC have the supportive care they need to manage their post-treatment symptoms.

The physical and emotional impacts resulting from HNC and its associated treatments are documented in the literature^{45–48} and were similarly experienced by the participants in this study. This included dysphagia, communication difficulties, alterations to dentition, mucositis, pain, weight loss, lymphedema, skin breakdown, psychological distress, and fatigue. Managing this diverse array of conditions necessitates complex care plans incorporating many medical, nursing, and allied health providers. This was a key finding of the current study with 21 different health professionals noted to be directly involved in the recovery stage of the current participants, and an additional 10 required for related, albeit indirect, medical needs.

Interestingly, the current study also found that rural participants needed access to a greater variety of professionals in their recovery compared with the metropolitan participants. Although the reason for this was not able to be ascertained in the data collected, it may be influenced by the fact that many rural people with HNC present with later stage disease and have greater delays in treatment commencement,^{18–20} necessitating more invasive treatment protocols with greater toxicities and side effects. Indeed, there was slightly more T3-4 stage patients in the rural cohort ($n = 4/6$ versus $2/5$). In addition to seeing a

larger number of professionals, it was also noted that in the rural group there was a duplication of professionals across hospital sites. Overall, while all participants had complex and convoluted care pathways, the metropolitan participants had the advantage of receiving all necessary services from the one hospital site and had one group of clinicians managing their health care needs.

Cumulatively, the service and access issues highlighted in this study also were found to heighten the psychological distress for many rural participants. While Patient 2 experienced distress associated with treatment complications, he did not report stress associated with accessing necessary health services/professionals. Comparatively, the rural experience described by Patient 1 highlighted multiple barriers and difficulties accessing necessary care, including lengthy travel burden and need to rely on family/friends, which compounded her stress levels. Traveling for care is known to cause additional financial, emotional, and psychological stress for both the person with HNC and their family.^{49–52} The current data highlight the importance of considering travel burden, and the additional challenge of arranging and co-ordinating care, faced by patients in rural areas.

Given the high health care utilization and the disproportionately higher number of difficulties faced by the rural participants in accessing coordinated, streamlined, and efficient care, it is necessary to look toward solutions to improving the recovery journey. Further research is needed to examine the causes for the service inequities identified, as well as a more thorough understanding of what is needed to support better co-ordinated local multi-disciplinary services to support people post-HNC care. Action is then needed to find solutions that will improve care co-ordination and reduce the burden of accessing care for our patients in rural areas.

4.1 | Limitations

Although there are acknowledged limitations in using patient diaries and self-reporting for data collection, the use of three points of data triangulation in this study aimed to minimize this. As not all participants provided specific dates for private appointments attended (e.g., general practitioners), these episodes were recorded on the journey maps without a specific date. Hence, results may represent underreporting of services accessed and may be interpreted as the minimum number attended. Participants of this study were recruited from a single HNC multidisciplinary clinic within a public health service, and therefore the results and experiences may not be reflective of other public/private services. Ten participants were lost to follow-up or asked to be removed from the study. Key demographics of age, sex,

and marital status were checked for differences to evaluate risk of bias; however, these were not significantly different. Working status and dependent children were not able to be ascertained as these data were not able to be collected during the interviews nor routinely collected in the electronic systems.

Additionally, the sample size was smaller than planned due to COVID-19, which truncated the recruitment window for this study. To validate the accuracy of the current data, post-study power calculations were run, which revealed values less than 0.8 for some of the comparisons. However, despite this, strong patterns of difference were still evident between the metropolitan and rural participants recruited. So, in order to further verify the reliability of the statistical analysis, a statistician subsequently undertook additional Bootstrapping analysis²⁹ (using 1000 replications) was conducted, which corroborated and confirmed the statistically significant differences found between the rural and metropolitan results. However further examination of larger cohorts across multiple health service districts may yield additional insights. Examining how disease staging, tumor type and treatment type impacted differences by rurality was outside of the scope of this study and would also be an important parameter to study in any future work.

5 | CONCLUSION

Through mapping the post-acute journey, this study has illustrated the complexity of the health care journey for people recovering from HNC treatment and the difficulties encountered in managing the number of professionals and services needed. Importantly, the results also highlight the disparity in service access and utilization between people with HNC living in metropolitan and rural areas. This disparity culminated in increased levels of distress and unmet need for rural participants. Future investigations into the barriers and facilitators impacting rural HNC care access and service delivery, especially for allied health professions who are central to managing the post-acute recovery, provide an opportunity to enhance the post-acute care journey for people with HNC living in rural areas.

ACKNOWLEDGMENT

Open access publishing facilitated by The University of Queensland, as part of the Wiley - The University of Queensland agreement via the Council of Australian University Librarians.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

All authors contributed to the study conception and design. Jasmine Foley lead and completed the data collection. Data analysis was completed by Jasmine Foley and Clare L. Burns. The first draft of the manuscript was written by Jasmine Foley and edited first by Clare L. Burns. All authors commented on subsequent versions of the manuscript. All authors read and approved the final manuscript.

ETHICS STATEMENT

Ethical approval was sought and granted by The Royal Brisbane and Women's Hospital Human Research Ethics Committee prior to commencement of the study (HREC/2018/QRBH/44912) and ratified by the University of Queensland Ethics Committee.

DATA AVAILABILITY STATEMENT

Data arising from this study are not publicly available to protect the privacy of participants. Access may be granted through request to the human research and ethics committee.

ORCID

Jasmine Foley  <https://orcid.org/0000-0001-7998-5372>

REFERENCES

1. Moroney LB, Helios J, Ward EC, et al. Patterns of dysphagia and acute toxicities in patients with head and neck cancer undergoing helical IMRT ± concurrent chemotherapy. *Oral Oncol.* 2016;64:1-8.
2. Barnhart MK, Robinson RA, Simms VA, et al. Treatment toxicities and their impact on oral intake following non-surgical management for head and neck cancer: a 3-year longitudinal study. *Support Care Cancer.* 2018;26(7):2341-2351.
3. Hewitt M, Ganz PA, Institute of M, National Research C. *From Cancer Patient to Cancer Survivor – Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium.* National Academies Press; 2006.
4. Nguyen N-TA, Ringash J. Head and neck cancer survivorship care: a review of the current guidelines and remaining unmet needs. *Curr Treat Options Oncol.* 2018;19(8):1-20.
5. Cancer Council Australia. *Optimal Care Pathway for People with Head and Neck Cancers.* Melbourne; 2016.
6. Paleri V, Roland N. Introduction to the United Kingdom National Multidisciplinary Guidelines for head and neck cancer. *J Laryngol Otol.* 2016;130(S2):S3-S4.
7. Cohen EEW, LaMonte SJ, Erb NL, et al. American Cancer Society head and neck cancer survivorship care guideline. *CA Cancer J Clin.* 2016;66(3):203-239.
8. Queensland Health. *The Allied Health Integrated Regional Pathway and Guide: Head and Neck Cancer Patients.* Queensland Health; 2014.
9. Dignonnet A, Hamoir M, Andry G, et al. Post-therapeutic surveillance strategies in head and neck squamous cell carcinoma. *Eur Arch Otorhinolaryngol.* 2013;270(5):1569-1580.

10. Manikantan K, Khode S, Dwivedi RC, et al. Making sense of post-treatment surveillance in head and neck cancer: when and what of follow-up. *Cancer Treat Rev*. 2009;35(8):744-753.
11. Joshi A, Calman F, O'Connell M, Jeannon JP, Pracy P, Simo R. Current trends in the follow-up of head and neck cancer patients in the UK. *Clin Oncol (R Coll Radiol)*. 2009;22(2):114-118.
12. Hartley D. Rural health disparities, population health, and rural culture. *Am J Public Health*. 2004;94(10):1675-1678.
13. Burris JL, Andrykowski M. Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psychooncology*. 2010;19(6):637-645.
14. Miles A, Proescholdbell R, Puffer E. Explaining rural/non-rural disparities in physical health-related quality of life: a study of United Methodist clergy in North Carolina. *Qual Life Res*. 2011;20(6):807-815.
15. Strong K. *Health in Rural and Remote Australia: the First Report of the Australian Institute of Health and Welfare on Rural Health*. Australian Institute of Health and Welfare; 1998.
16. World Health Organization. *Increasing Access to Health Workers in Remote and Rural Areas through Improved Retention Global Policy Recommendations*. WHO; 2010.
17. Ringstrom MJ, Christian J, Bush ML, Levy JE, Huang B, Gal TJ. Travel distance: impact on stage of presentation and treatment choices in head and neck cancer. *Am J Otolaryngol*. 2018;39(5):575-581.
18. Queensland Government. *Queensland Head and Neck Cancer Quality Index: Indicators of safe, quality cancer care, public and private hospitals 2011-2015* Brisbane 2019.
19. Tan JYA, Otty ZA, Vangaveti VN, et al. A prospective comparison of times to presentation and treatment of regional and remote head and neck patients in North Queensland, Australia. *Int Med J*. 2016;46(8):917-924.
20. Alho O-P, Teppo H, Mantyselka P, Kantola S. Head and neck cancer in primary care: presenting symptoms and the effect of delayed diagnosis of cancer cases. *CMAJ. Can Med Assoc J*. 2006;174(6):779-784.
21. Noel CW, Forner D, Wu V, et al. Predictors of surgical readmission, unplanned hospitalization and emergency department use in head and neck oncology: a systematic review. *Oral Oncol*. 2020;111:105039.
22. Shenson JA, Craig JN, Rohde SL. Effect of preoperative counseling on hospital length of stay and readmissions after Total laryngectomy. *Otolaryngol Head Neck Surg*. 2017;156(2):289-298.
23. Tsai W-C, Kung P-T, Wang S-T, Huang K-H, Liu S-A. Beneficial impact of multidisciplinary team management on the survival in different stages of oral cavity cancer patients: results of a nationwide cohort study in Taiwan. *Oral Oncol*. 2015;51(2):105-111.
24. Graboyes EM, Kallogjeri D, Saeed MJ, Olsen MA, Nussenbaum B. Postoperative care fragmentation and thirty-day unplanned readmissions after head and neck cancer surgery. *Laryngoscope*. 2017;127(4):868-874.
25. Henry M, Habib L-A, Morrison M, et al. Head and neck cancer patients want us to support them psychologically in the post-treatment period: survey results. *Pall Supp Care*. 2014;12(6):481-493.
26. Giuliani M, McQuestion M, Jones J, et al. Prevalence and nature of survivorship needs in patients with head and neck cancer. *Head Neck*. 2016;38(7):1097-1103.
27. Australian Bureau of Statistics. Australian statistical geography standard (ASGS). Australian Government. Accessed March 4 March, 2019. [https://www.abs.gov.au/websitedbs/d3310114.nsf/home/australian+statistical+geography+standard+\(asgs\)](https://www.abs.gov.au/websitedbs/d3310114.nsf/home/australian+statistical+geography+standard+(asgs)). 2018.
28. Given LM. *The SAGE Encyclopedia of Qualitative Research Methods*. SAGE Publications; 2008.
29. Dwivedi AK, Mallawaarachchi I, Alvarado LA. Analysis of small sample size studies using nonparametric bootstrap test with pooled resampling method. *Stat Med*. 2017;36(14):2187-2205.
30. Google. Road map driving distances in Queensland. Accessed September, 2020. <https://www.google.com/maps>. n.d.
31. Simonse L, Albayrak A, Starre S. Patient journey method for integrated service design. *Design Health*. 2019;3(1):82-97.
32. McCarthy S, O'Raghallaigh P, Woodworth S, Lim YL, Kenny LC, Adam F. An integrated patient journey mapping tool for embedding quality in healthcare service reform. *J Decision Syst*. 2016;25(supp 1):354-368.
33. Kelly J, Wilden C, Herman K, Martin G, Russell C, Brown S. Bottling knowledge and sharing it - using patient journey mapping to build evidence and improve Aboriginal renal patient care. *Renal Soc Australas J*. 2016;12(2):48-55.
34. Meyer MA. Mapping the patient journey across the continuum: lessons learned from one patient's experience. *J Patient Exp*. 2019;6(2):103-107.
35. Kerauala CJ, Newlands C, Coombes D. Follow-up after treatment of squamous cell carcinoma of the oral cavity: current maxillofacial practice in the United Kingdom. *Br J Oral Maxillofac Surg*. 2007;45(5):361-363.
36. Kanatas A, Bala N, Lowe D, Rogers SN. Outpatient follow-up appointments for patients having curative treatment for cancer of the head and neck: are the current arrangements in need of change? *Br J Oral Maxillofac Surg*. 2014;52(8):681-687.
37. Wells M, Semple CJ, Lane C. A national survey of healthcare professionals' views on models of follow-up, holistic needs assessment and survivorship care for patients with head and neck cancer. *Eur J Cancer Care*. 2015;24(6):873-883.
38. Rocke J, McLaren O, Hardman J, et al. The role of allied healthcare professionals in head and neck cancer surveillance: a systematic review. *Clin Otolaryngol*. 2020;45(1):83-98.
39. Kissun D, Magennis P, Lowe D, Brown J, Vaughan E, Rogers S. Timing and presentation of recurrent oral and oropharyngeal squamous cell carcinoma and awareness in the outpatient clinic. *Br J Oral Maxillofac Surg*. 2006;44(5):371-376.
40. Stevenson L, Campbell NC, Kiehlmann PA. Providing cancer services to remote and rural areas: consensus study. *Br J Cancer*. 2003;89(5):821-827.
41. Bain NSC, Campbell NC. Treating patients with colorectal cancer in rural and urban areas: a qualitative study of the patients' perspective. *Fam Pract*. 2000;17(6):475-479.
42. Mickan SM. Evaluating the effectiveness of health care teams. *Aust Health Rev*. 2005;29(2):211-217.
43. Cancer Australia Head and neck cancer; 2018. <https://head-neck-cancer.canceraustralia.gov.au/statistics>. Accessed March 30, 2019.

44. Queensland Health. *Cancer Care Statewide Health Service Strategy 2014*. Queensland Health; 2014.
45. García-Peris P, Parón L, Velasco C, et al. Long-term prevalence of oropharyngeal dysphagia in head and neck cancer patients: impact on quality of life. *Clin Nutr*. 2007;26(6):710-717.
46. Ghazali N, Kanatas A, Scott B, Lowe D, Zuydam A, Rogers SN. Use of the patient concerns inventory to identify speech and swallowing concerns following treatment for oral and oropharyngeal cancer. *J Laryngol Otol*. 2012;126(8):800-808.
47. Logemann JA, Rademaker AW, Pauloski BR, et al. Site of disease and treatment protocol as correlates of swallowing function in patients with head and neck cancer treated with chemoradiation. *Head Neck*. 2006;28(1):64-73.
48. Muz J, Mathog RH, Hamlet SL, Davis LP, Kling GA. Objective assessment of swallowing function in head and neck cancer patients. *Head Neck*. 1991;13(1):33-39.
49. Burns CL, Kularatna S, Ward EC, Hill AJ, Byrnes J, Kenny LM. Cost analysis of a speech pathology synchronous telepractice service for patients with head and neck cancer. *Head Neck*. 2017;39(12):2470-2480.
50. Butow P, Phillips F, Schweder J, White K, Underhill C, Goldstein D. Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Support Care Cancer*. 2012;20(1):1-22.
51. Beswick DM, Vashi A, Song Y, et al. Consultation via telemedicine and access to operative care for patients with head and neck cancer in a veterans Health administration population. *Head Neck*. 2016;38(6):925-929.
52. Rogers SN, Harvey-Woodworth C, Hare J, Leong P, Lowe D. Patients' perception of the financial impact of head and neck cancer and the relationship to health related quality of life. *B J Oral Maxillofac Surg*. 2012;50(5):410-416.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Foley J, Burns CL, Ward EC, et al. Post-acute health care needs of people with head and neck cancer: Mapping health care services, experiences, and the impact of rurality. *Head & Neck*. 2022;44(6):1377-1392. doi:[10.1002/hed.27037](https://doi.org/10.1002/hed.27037)