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

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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.
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, making ongoing supportive care and monitoring critical in the post-treatment phase. 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.

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. 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, with most attention focusing only on specialist medical surveillance for disease recurrence.

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, 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, 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. These factors are known to contribute toward higher risk of death at 3-year follow-up. Rurality and distance from treating center has also been reported as a risk factor for unplanned hospital readmissions and 30-day emergency department use 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.

Given the complex care requirements, it is not surprising that studies suggest up to 60% of people with HNC have unmet care needs. 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 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 heroin referred to as rural (regional and remote areas). The Australian Statistical Geography Standard (ASGS) Remoteness Structure 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). 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
distances and as this

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Previous use of journey mapping in the evaluation of rural renal health care found the process beneficial, 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. 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. 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. 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.

In this study, we adapted and modified a longitudinal patient journey map published by Meyer 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, Brown 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 tumors (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
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

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**TABLE 1 Whole cohort demographics and characteristics**

| Demographics and characteristics | No. participants in total cohort | Subgroup analysis |
|----------------------------------|----------------------------------|-------------------|
|                                  | \(n (\%)\)                       | No. of metropolitan participants | No. of rural participants |
|                                  | \(n (\%)\)                       | \(n (\%)\)         | \(n (\%)\)         |
| Age group                        |                                  | 11 (100)          | 5 (45.5)          | 6 (54.5)          |
| 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 FEG                 |                                  |                   |                   |
| 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.
TABLE 2  Services accessed by all participants during 6-month post-acute recovery period

|                | Number of attended appointments | No. of appointments attended for HNC specialists, n (%) | No. of appointments attended for non-HNC specialists, n (%) | No. of all FTA & canceled appointments | 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 |
|----------------|--------------------------------|-------------------------------------------------------|-----------------------------------------------------------|----------------------------------------|-----------------------------------------------|-----------------------------------------------|---------------------------------|-------------------------------------|
| 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                                  |
| Median          | 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                                   |
| Median          | 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.
*For 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 | Medical Oncologist | Medical Oncologist |
| Radiation Oncologist | Radiation Oncologist |
| Medical Oncologist | Medical 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 Speech Pathology | Dietetics |
| Dietetics | Psychology |
| Psychology | Social Work |
| Social Work | Physiotherapy |
| Physiotherapy | Occupational Therapy |
| Occupational Therapy | Cancer Care Services |
| Cancer Care Services | Nursing |
| Nursing | Wound Clinic |
| Wound Clinic | Emergency Department |
| Emergency Department | Hospital Avoidance |
| Hospital Avoidance | Program |

| Indirectly needed for head and neck cancer recovery | Endocrinology | Endocrinology |
|-----------------------------------------------------|---------------|---------------|
| Urology | Urology |
| Respiratory Specialists | Respiratory Specialists |
| Anesthetics | Anesthetics |
| Infectious Diseases | Infectious Diseases |
| General Surgeon | General Surgeon |
| Immunology | Immunology |
| Cardiology | Cardiology |
| Cardiac Rehabilitation | Cardiac Rehabilitation |
| Thoracic Specialist | 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...
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

| 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 |
| **Median**  | Private car  | 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 |
| **Median**  | Private car  | 0 h 45 min | 8 h 30 min |
| Date    | Visit site | Service                  | Reason                                                                 |
|---------|------------|--------------------------|------------------------------------------------------------------------|
| 6 Aug   |            | Initial appointment on return home |
| 7-13 Aug|            | Multiple Phone r/v to metro nurse; Expectating blood; Told to attend local ED |
| 9 Aug   |            | Minor procedure          |
| 13 Aug  |            | Assessment of skin donor site on wrist |
| 14 Aug  |            | Changed dressings to neck |
| 14 Aug  |            | Initial phone review     |
| 27 Aug  |            | Advised to drive to Metro. Given antibiotics |
| 30 Aug  |            | Pt reported difficulties with odynaphagia & dysphagia. Contacted regional SP but unable to travel to appointment. Metro SP liaised with regional SP & RD |
| 3 Sept  |            | Lymphoedema management and r/v of skin donor wound on wrist. Booked for regional SP/DT at same time & unable to attend |
| 4 Sept  |            | Attended site due booking error & sent home without r/v |
| 10 Sept |            | Planned monitoring appointment |
| 16 Sept |            | Initial appointment      |
| 17 Sept |            | Planned monitoring appointment |
| 18 Sept |            | Phone review             |
| 19 Sept |            | Fail to attend           |
| 23 Sept |            | Initial appointment      |
| 24 Sept |            | Lymphoedema complication needing urgent management |
| 25 Sept |            | Routine management with blood tests, pain review and check on odynaphagia |
| 26 Sept |            | Cancelled by hospital    |
| 1 Oct   |            | Cancelled by hospital    |
| 2 Oct   |            | Weight loss & nutritional education. Tongue exercises |
| 8 Oct   |            | Monitoring of skin donor site on wrist |
| 9 Oct   |            | Lymphoedema management   |
| 9 Oct   |            | Ongoing weight monitoring & management |
| 10 Oct  |            | CT scan                  |
| 11 Oct  |            | Planned review and monitoring |
| 16 Oct  |            | Weight loss monitoring and blood test |
| 17 Oct  |            | Lymphoedema management   |
| 23 Oct  |            | Management of dysphagia, xerostomia & weight loss |
| 29 Oct  |            | Management of dysphagia, xerostomia & weight loss |
| 5 Nov   |            | Monitoring of skin donor site on wrist; d/c from service |
| 6 Nov   |            | Lymphoedema management   |
| 7 Nov   |            | Lymphoedema management   |
| 11 Nov  |            | Lymphoedema management   |
| 12 Nov  |            | Dysphagia and weight loss management |
| 14 Nov  |            | Lymphoedema management   |
| 20 Nov  |            | Develop care plan        |
| 21 Nov  |            | Lymphoedema care plan    |
| 2 Dec   |            | Dysphagia and weight loss management |
| 5 Dec   |            | Check lymphoedema mask   |
| 10 Dec  |            | Lymphoedema management   |
| 12 Dec  |            | Lymphoedema management   |
| 16 Dec  |            | Planned review of oral wound healing |
| 9 Jan   |            | Lymphoedema management   |

**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]
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

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

**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]
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. While there is no international consensus on the frequency of follow-up appointments, many protocols advocate for reviews to be scheduled as much as monthly, and up to third monthly, in the first year. 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. 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. In contrast, the focus of allied health and nursing professionals in the follow-up period is on quality of life and symptom management. However, these services are usually booked on an ad-hoc basis, 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 Kingdom; 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 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. This need for integrated and coordinated health networks is not a new concept in cancer care 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 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, 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. 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 multidisciplinary 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 analysis\(^\text{39}\) (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.

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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.

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**SUPPORTING INFORMATION**

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

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