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# Exploring transitions in care among patients with head and neck CANCER: a multimethod study

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## Abstract

**Background** Patients with head and neck cancers (HNC) experience many transitions in care (TiC), occurring when patients are transferred between healthcare providers and/or settings. TiC can compromise patient safety, decrease patient satisfaction, and increase healthcare costs. The evidence around TiC among patients with HNC is sparse. The objective of this study was to improve our understanding of TiC among patients with HNC to identify ways to improve care.

**Methods** This multimethod study consisted of two phases: Phase I (retrospective population-based cohort study) characterized the number and type of TiC that patients with HNC experienced using deterministically linked, population-based administrative health data in Alberta, Canada (January 1, 2012, to September 1, 2020), and Phase II (qualitative descriptive study) used semi-structured interviews to explore the lived experiences of patients with HNC and their healthcare providers during TiC.

**Results** There were 3,752 patients with HNC; most were male (70.8%) with a mean age at diagnosis of 63.3 years (SD 13.1). Patients underwent an average of 1.6 (SD 0.7) treatments, commonly transitioning from surgery to radiotherapy (21.2%). Many patients with HNC were admitted to the hospital during the study period, averaging 3.3 (SD 3.0) hospital admissions and 7.8 (SD 12.6) emergency department visits per patient over the study period. Visits to healthcare providers were also frequent, with the highest number of physician visits being to general practitioners (average = 70.51 per patient). Analysis of sixteen semi-structured interviews (ten patients with HNC and six healthcare providers) revealed three themes: (1) Navigating the healthcare system including challenges with the complexity of HNC care amongst healthcare system pressures, (2) Relational head and neck cancer care which encompasses patient expectations and relationships, and (3) System and individual impact of transitions in care.

**Conclusions** This study identified challenges faced by both patients with HNC and their healthcare providers amidst the frequent TiC within cancer care, which was perceived to have an impact on quality of care. These findings provide crucial insights that can inform and guide future research or the development of health interventions aiming to improve the quality of TiC within this patient population.

**Keywords** Oncology, Otolaryngology, Canada, Care transitions, Continuity of care

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## Background

Head and Neck Cancers (HNC) are a group of cancers that affect diverse anatomical structures including the pharynx, larynx, naso-, oro-, hypopharynx, nasal cavity, oral cavity, middle ear, and salivary glands [1]. HNC are the sixth most common cancer in the world [2] accounting for approximately 931,931 new diagnoses worldwide each year, with a projected 30% annual increase by the year 2030 [1, 3]. There are several risk factors for HNC which include alcohol and tobacco use, malnutrition, lower socioeconomic status, age, sex, exposure to carcinogens and contracting the Human Papilloma Virus (HPV) [4, 5]. The presence of these risk factors results in differences in disease presentation, progression, and patient outcomes [6, 7]. Although the 5-year age-standardized survival rates for HNC vary between countries and the site of the HNC, they remain relatively low, with age standardized estimates ranging from 2.5 to 8.3 per 100,000 [8–11].

Patients with HNC are cared for by multidisciplinary healthcare teams which collaboratively develop treatment plans, manage treatment sequelae, and provide comprehensive supportive care and rehabilitation [12, 13]. These treatment plans often include a combination of surgery, radiation, chemotherapy, and immunotherapy [12, 14]. As a result of their complex treatment plans, and vulnerability to physical and psychological effects from HNC and its associated treatments, patients with HNC are some of the highest users of healthcare resources [15–17]. As this patient population requires care from many healthcare providers across different healthcare settings, they consequently experience many transitions in care (TiC) [12, 18, 19]. TiC occur when the responsibility for a patient's care is transferred between healthcare providers, institutions, or settings [20]. TiC can also occur when patients move from one level of care to another (e.g., from the intensive care unit to the hospital ward) [20]. TiC represent a challenging period in the delivery of care as they interrupt continuity of care, opening opportunities for inadequate transfer of information and potential breakdown in communication [21]. In other patient populations, poorly executed TiC have been associated with compromised patient safety, increased medical errors, high distress levels in patients and their families, excessive healthcare cost and resource use [22–27]. As such, organizations such as the Joint Commission and the National Academy of Medicine have identified a critical need to effectively bridge the TiC that patients experience to help mitigate adverse effects on patient health outcomes [28, 29]. Despite the complex multidisciplinary care of patients with HNC and the established risks of poor care during TiC, there is a gap in our understanding of TiC for patients with HNC.

The objectives of this study are to (1) estimate the number and type of TiC patients with HNC experience, (2)

understand TiC from the perspective of patients with HNC and healthcare providers, (3) explore the quality of care during TiC, from the perspective of patients with HNC and healthcare providers.

## Methods

This multimethod study was approved by the University of Calgary Health Research Ethics Board of Alberta (HREABA.CC-20-0474) and consisted of two distinct phases: a retrospective population-based cohort study and a qualitative descriptive study.

### Phase 1: retrospective cohort study

#### Setting

This study was conducted in Alberta, Canada where healthcare services are provided by a provincially integrated single-payer healthcare system (Alberta Health Services (AHS)) [30, 31]. AHS is the largest integrated provincial healthcare system in Canada [31] composed of 106 acute care hospitals, five psychiatric facilities, and partners with 40 primary care networks [30]. Cancer care for patients with HNC is delivered by AHS in two main cancer care centres in Alberta: Tom Baker Cancer Centre in Calgary and the Holy Cross Cancer Centre in Edmonton [30, 31].

#### Population and data sources

This retrospective population-based cohort study quantitatively characterized the number and type of TiC that patients with HNC experience throughout their cancer journey, using routinely collected, population-based administrative health data. The cohort included adult patients ( $\geq 18$  years old) diagnosed with HNC in Alberta between January 1, 2012, to September 1, 2020, as indicated by a record in the population-based Alberta Cancer Registry (ACR).

Data from four administrative health data sources were deterministically linked using a unique personal healthcare number that is assigned to each person in the province at birth or immigration to the province and follows them throughout their life. The ACR, a population-based registry, records patient demographic information (name, date of birth, sex, postal code) and cancer-specific variables (diagnosis with dates, pathology, treatments with dates, and staging) [32]. The Discharge Abstract Database (DAD) includes information on acute care hospital admissions including demographics, diagnoses (using the International Classification of Disease version 10 (ICD-10) codes), procedures, and admission and discharge information [33]. Physician billing claims include diagnostic codes (ICD-9) assigned by physicians used to bill the Government of Alberta for services provided to patients. The National Ambulatory Care Reporting System (NACRS) collects demographic, administrative, clinical, and service-specific

data from both hospital-based and community-based ambulatory care visits [34, 35].

### Variables

Patient demographic variables (age, sex, and socioeconomic status), cancer-related variables (site, stage, and presence of multiple tumours) and treatment-related variables (treatment modalities) were extracted from ACR. The Charlson Comorbidity Index (categorized as 0,1,2+) was calculated using established coding algorithms [36].

The primary outcome variables were the number and type of TiC. The TiC examined included the transitions between treatments, healthcare institutions (hospital visits and associated discharges, emergency department visits), and different healthcare providers. The type of TiC variables were dichotomously coded, with a 0 indicating that a patient did not experience a TiC and a 1 that a patient experienced a TiC (Supplementary Table 1). TiC rates were computed individually for each patient across four distinct periods: six months before diagnosis, from diagnosis to initial treatment, one-year post-first treatment, and three years post-first treatment.

### Analysis

The cohort characteristics were described using descriptive statistics; means with standard deviations (SD) or medians and interquartile ranges (IQR) where appropriate, and frequencies (proportions). The TiC rates were calculated as number per month across the 4 periods described above. All analyses were conducted using STATA 16 SE [37]. This phase is reported according to the STrengthening the Reporting of Observational Studies in Epidemiology (STROBE) and the REporting of studies Conducted using Observational Routinely-collected Data (RECORD) (Appendix 1) [38, 39].

### Phase 2: qualitative description

The qualitative descriptive study followed the general tenets of naturalistic inquiry to provide a richer understanding of TiC and care delivery among patients with HNC and their healthcare providers [40, 41]. In-depth, semi-structured interviews were conducted with two participant groups: (1) adult patients with HNC, who received care in Alberta, at any stage of their cancer journey and (2) multi-professional healthcare providers who care for patients with HNC in Alberta. This phase was reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Appendix 2) [42].

### Participants and recruitment

Recruitment occurred between September 1, 2022, to July 15th, 2023. Different sampling strategies were

employed for the two participant groups. Patients with HNC were recruited through purposive sampling and employed media-based approaches to ensure maximum variation in patient characteristics [43]. Healthcare providers were also recruited through purposive sampling, using the researchers' professional networks. All potential participants were provided with the contact information for the principal investigator.

### Data collection

Interviews were completed using semi-structured interview guides uniquely developed for each participant group, informed by our methodological framework. These guides included open-ended questions relevant to the objectives of the study and probing questions to elicit data [44]. The interview guides were pilot-tested within the research team and iteratively refined by the authors (J.K and K.M.S).

Semi-structured interviews were conducted via telephone ( $n=2$ ) or secure video conferencing platform (Zoom) ( $n=14$ ) [45] with no other participants present. The interviews were conducted by the first author (J.K) who has formal graduate training and practical experience in qualitative methods and interview facilitation. The interviewer did not have any previous relationships with patients with HNC, however, due to the sampling method for healthcare professionals, the interviewer had a professional relationship with one of the included healthcare providers. The interviews were audio recorded and transcribed verbatim using transcription services (rev.com), with a unique study identifier replacing the participant's name. Participants were recruited and data was collected until saturation was reached. Saturation was achieved when no novel themes were generated from the data [46].

Written, informed consent was obtained from all participants before participating in the semi-structured interviews. Additional consent was received from all participants to audio record the interviews and to use anonymized quotations in research publications and dissemination.

### Data analysis

The data from the semi-structured interviews was analyzed using an inductive approach, whereby two independent reviewers (J.K and K.M.S) followed Braun and Clarke's approach to thematic analysis [46]. Thematic analysis was facilitated by the qualitative software Nvivo [47]. The themes from the patients with HNC and the healthcare providers were also compared and contrasted to ensure alignment to an overarching central concept [48]. Qualitative analysis and generated themes were discussed with the study team to facilitate peer debriefing [41].

**Reflexivity**

The interview facilitator and first analyst (J.K) was a graduate student (MSc), familiar with evidence suggesting that TiC are vulnerable periods for patients. The second analyst (K.M.S) was an Assistant Professor whose broad research area encompassed TiC among patients with HNC. Due to their previous experiences and knowledge, both researchers acknowledged that their perception of TiC may be inherently negative and this was frequently debriefed with the team in order to consciously reduce any impact on their findings. Throughout the research process, the reviewers also critically examined their assumptions and challenged them to mitigate any potential bias.

**Results**

**Retrospective cohort study**

The cohort included 3,752 patients with HNC. Demographic characteristics of the cohort are presented in Table 1. Briefly, most patients were male (70.8%) and had a mean age at diagnosis of 63.3 years (SD = 13.1).

The overall, all-cause mortality of patients was 44.86% (n=1,683) within the study period. The mean number of TiC per patient was 210.3 (SD=164.6). The mean TiC rate per patient was 7.7 (SD=10.2) during the six months preceding diagnosis. Following diagnosis and before the first treatment, the mean TiC rate per patient increased to 23.1 (SD=34.9) per patient. Subsequently, the mean TiC rate per patient declined to 4.2 (SD=5.3) one year post-first treatment with a further decrease to 2.0 (SD=2.2) per patient three years post-first treatment. Patients with HNC had frequent transitions between different treatments. A total of 47.9% of patients underwent two or more treatments during the study period, with an average of 1.6 (SD=0.7) treatments per patient. The most common treatment was radiotherapy, followed closely by surgery; the most common treatment transition was the transition from surgery to radiotherapy (21.2%) (Table 2).

Many patients with HNC were admitted to the hospital during the study period (Table 3), with an average of 3.3 (SD=3.0) hospital admissions per patient. When patients were admitted to hospital, frequently they were admitted from home (82.6%) and discharged to home with no support (as indicated in their discharge report; 82.8%) (Table 3). Visits to an emergency department were common (n=3,475 patients) with an average of 7.8 (SD=12.6) visits per patient during the study period. The number of emergency department visits increased after diagnosis and again after the first treatment (Table 4). The highest number of physician visits were to general practitioners (family medicine) (average=70.6 per patient) followed by other specialists (average=65.2 per patient; Table 5). The number of visits to most healthcare providers increased after diagnosis (Table 5).

**Table 1** Demographic characteristics of the cohort

Characteristic	Total (N= 3,752)
Age at Diagnosis, yr, mean (SD)	63.3 (13.1)
Age at Admission, yr, mean (SD)	63.6 (13.1)
Sex	% (n)
Male	70.8 (2,657)
Female	29.2 (1,095)
Stage of Cancer	% (n)
0	-
I	15.2 (571)
II	9.1 (342)
III	10.0 (377)
IV	42.0 (1,575)
Unknown	6.7 (251)
Not available	16.7 (626)
Missing <sup>a</sup>	0.3 (10)
Cancer Site	% (n)
Accessory Sinuses	2.0 (75)
Base of tongue	11.3 (425)
Floor of mouth	4.4 (166)
Gum	3.2 (122)
Hypopharynx	2.2 (81)
Larynx	13.2 (497)
Lip	3.1 (116)
Salivary glands	1.5 (55)
Mouth	5.2 (197)
Nasopharynx	4.4 (164)
Oropharynx	4.2 (158)
Palate	2.7 (102)
Parotid Gland	6.9 (258)
Pyiform Sinus	2.4 (89)
Tongue	15.3 (575)
Tonsil	14.5 (543)
Nasal Cavity & Middle Ear	2.8 (107)
Other	0.6 (22)
Number of Tumours	% (n)
1	93.6 (3,513)
2	6.4 (239)
Charlson Comorbidity Index	% (n)
0	23.1 (866)
1	8.0 (300)
2	68.9 (2,586)

<sup>a</sup> Missing indicates that there is no patient data available

**Qualitative description**

Sixteen interviews (ten patients and six healthcare providers) were conducted between July 17<sup>th</sup>, 2022, to June 7<sup>th</sup>, 2023. The interviews ranged between 30 and 90 min (median=46 min). The mean age of patients with HNC at the time of the interview was 66 years old (range=47–77 years), most were female (n=7, 70%) and experienced

**Table 2** Transitions in care related to treatment

Category	Total <sup>a</sup> (N= 3,752)
Treatment	% (n)
Surgery	46.7 (1,753)
Radiotherapy	48.4 (1,816)
Chemotherapy	23.3 (873)
Immunotherapy	2.0 (77)
Hormonotherapy	0.4 (15)
Observation	0.6 (21)
Refused	2.0 (77)
Trial	0.05 (2)
Other	0.13 (5)
Number of Treatments	% (n)
Treatments per patient, mean (SD)	1.6 (0.7)
0	2.9 (109)
1	40.6 (1,522)
2	38.7 (1,451)
3+	9.2 (347)
missing	8.6 (323)
Transition in Care	% (n)
Diagnosis to Treatment	73.3 (2,752)
Surgery to Radiotherapy	21.2 (794)
Radiotherapy to Chemotherapy	18.4 (689)
Chemotherapy to Radiotherapy	4.2 (157)
Immunotherapy to Radiotherapy	1.5 (56)
Surgery to Chemotherapy	1.0 (38)
Radiotherapy to Surgery	0.35 (13)
Surgery to Immunotherapy	0.32 (12)
Immunotherapy to Chemotherapy	0.05 (2)
Immunotherapy to Surgery	0.03 (1)
Chemotherapy to Surgery	0.32 (12)
Chemotherapy to Immunotherapy	0.19 (7)
Chemotherapy to Trial	0.03 (1)
Surgery to Hormonotherapy	0.32 (12)
Radiotherapy to Immunotherapy	0.16 (6)
Hormonotherapy to Surgery	0.05 (2)
Hormonotherapy to Other	0.13 (5)
Trial to Radiotherapy	0.03 (1)

<sup>a</sup> Totals may be greater than 100% as 40% of patients experienced multiple treatments

many TiC. Healthcare providers included surgeons ( $n=3$ ), a medical oncologist ( $n=1$ ), a radiation oncologist ( $n=1$ ), and a licensed practical nurse ( $n=1$ ). The healthcare providers were mostly male ( $n=4$ ), with the average years of practice being 21 years (range=7.5–31 years).

**Themes**

The qualitative analysis generated three interconnected themes: (1) Navigating the Healthcare System (sub-themes: head and neck cancer care complexities, disrupted continuity of head and neck cancer care, and

**Table 3** Transitions in care related to hospital admissions

Transition in Care	Total (N= 3,752)
Hospital Visits	% (n)
Hospital Visits per patient, mean (SD)	3.3 (3.0)
Home to Hospital	82.6 (3,098)
Emergency Department to Hospital	63.2 (2,372)
Other Setting to Hospital	16.2 (607)
Hospital Discharges	% (n)
Hospital to Home (with support)	42.4 (1,590)
Hospital to Home (without support)	82.8 (3,106)
Hospital to Acute Care Inpatient Institution	13.5 (508)
Hospital to Other Healthcare Facility	2.8 (105)
Hospital to Continuing Care	3.9 (145)
Left against Medical Advice	2.6 (99)
Patients not returning from pass	6.4 (240)
Died	14.5 (544)

**Table 4** Transitions in care related to emergency department visits

Transition in Care	Total (N= 3,752)
Emergency Department (ED) visits per patient, mean (SD)	7.8 (12.6) <sup>a</sup>
Type of ED visit	% (n) <sup>b</sup>
ED visits pre-diagnosis	67.6 (2,536)
ED visits post-diagnosis	78.8 (2,955)
ED visits pre-first treatment	74.9 (2,809)
ED visits post-first treatment	58.9 (2,209)

<sup>a</sup> The number of ED visits indicated is cumulative for the study period

<sup>b</sup> ED visits sum to greater than 100% as post-diagnosis and pre and post first treatment ED visits overlap

**Table 5** Physician visits

Physician Visit	Per Patient (N= 3,752)
General Practitioner	70.6 (264552/3,746)
General practitioner visits pre-diagnosis	35.4 (123897/3,500)
General practitioner visits post-diagnosis	45.0 (140504/3,118)
Ear, Nose, Throat Specialist	6.9 (7134/1,025)
Ear, Nose, Throat Specialist pre-diagnosis	5.9 (1682/284)
Ear, Nose, Throat Specialist post-diagnosis	6.6 (5451/820)
Oncologist	2.3 (975/426)
Oncologist pre-diagnosis	1.9 (340/175)
Oncologist post-diagnosis	2.3 (635/271)

healthcare system pressures), (2) Relational Head and Neck Cancer Care (subthemes: patient expectations during Transitions in Care, feeling valued as a Head and



Neck Cancer patient and healthcare provider roles and responsibilities) and (3) System and Individual Impact of Transitions in Care (subthemes: impact of resource-intensive nature of TiC and the Impact of Transitions in Care on Quality of Care). Additional exemplar quotations for each theme are presented in Table 6.

#### **Navigating the healthcare system**

Despite the healthcare system's overarching goal of providing high-quality care, participants expressed struggles with navigating complex healthcare systems, leading to poor quality of care.

#### **Head and neck cancer care complexities**

While both patients with HNC and healthcare providers reported that navigating the complexities of HNC care is challenging, healthcare providers noted the necessity for multidisciplinary care, while patients described confusion by the care pathways used during their treatment. Patients perceived their care to be overly complex, involving many healthcare disciplines and many of the processes were unfamiliar to them. Although healthcare providers recognized the need for care pathways, guidelines, and protocols to ensure standardized care, they also recognized that patients did not intuitively know how to navigate these complex pathways and the health system.

#### **Disrupted continuity of head and neck cancer care**

Patients and healthcare providers described a siloed healthcare system which affected all aspects of patient care, hindering communication, resulting in prolonged waits, and disrupting the continuity of care. There were many instances where healthcare silos were identified as the cause of communication breakdowns among patients with HNC and their healthcare providers, with patients struggling to contact the appropriate healthcare providers and the communication between the multidisciplinary healthcare teams becoming strained. However, only patients with HNC associated the siloed healthcare system structure with prolonged waits and fragmented care, reporting wait times of five to six weeks between different healthcare departments (surgery, dermatology, and psychiatry) and lapses in continuous care. Healthcare silos were physical and geographical, requiring patients to travel to different healthcare institutions for their care.

Patients with HNC and healthcare providers proposed potential solutions which they felt could address these issues, including consolidating healthcare teams and departments into a centralized facility and the direct communication via telephone between patients, oncologists, and other healthcare providers.

#### **Healthcare system pressures**

Patients with HNC and healthcare providers recognized that a prominent constraint facing the healthcare system is the shortage of trained healthcare professionals. Patients with HNC described inadequate access to healthcare providers, specifically primary care providers and psychologists who they felt were critical to their care. Healthcare providers commonly noted that constrained human resources necessitated taking on additional responsibilities beyond their designated roles, often without appropriate support or adjustment to their workload. Healthcare providers, most notably specialists, were sometimes placed into uncomfortable situations where patients expected them to manage their daily care which is beyond their scope of practice.

#### **Relational head and neck cancer care**

Patients with HNC and healthcare providers identified interconnected factors including patients' expectations of their care, their perception of being valued within the healthcare system and their understanding of healthcare provider roles and responsibilities that influenced how patients experienced their healthcare journey and TiC.

#### **Patient expectations during transitions in care**

Patient expectations of the healthcare system and their care were pivotal in shaping their experiences with cancer care. Some patients faced difficulties aligning what they anticipated their care to look like with the actual care they received. Patients struggled to establish expectations for their TiC that were aligned with their actual care due to their unfamiliarity with the complex healthcare system and the complexity of HNC care. These divergent expectations were especially evident during the transition from active treatment to survivorship when a patient's interactions with the healthcare team dramatically decreased. Expectations of care not being met also led to heightened frustration and stress among patients with HNC. However, patients hesitated to voice these feelings with their healthcare providers for fear of being labelled as "high maintenance" when advocating for their needs.

#### **Feeling valued as a head and neck cancer patient**

Emotional support during the cancer continuum was perceived to be crucial by patients with HNC and healthcare providers. The healthcare providers noted that professional psychological care, although in short supply, is a key source of support. However, patients perceived the existing patient-provider relationship as an equally crucial source of support. Strong patient-provider relationships were rooted in mutual knowledge, respect, and trust and thrived when healthcare

**Table 6** Exemplar quotations for the qualitative themes from the semi-structured interviews

Theme	Subtheme	Exemplar Quotes
Navigating the healthcare system	HNC care complexities	<p>"I think arguably more than other cancer types, the treatment for head and neck cancer is just so complicated and complex and involves so many different healthcare providers that the more people you involve, the more transitions there are. It just means that at every transition point, there needs to be some tool, or some means to make sure that the critical aspects of a patient's care are being transferred from one person to another or from one location to another. I think transitions are not just from one person to another it is also location as well. And that journey continues endlessly... there are just many potential transitions points within a patient's journey... every one of those represents a point of vulnerability where things could potentially be miscommunicated, and you know I see that as a potential opportunity for mistakes to happen or for misadventures to happen." (Healthcare Provider 1)</p> <p>"If patients have issues, number one, they don't know what the issue is. If it is just a general issue, "I feel nauseated," who do they call? They can call the radiation oncologist, they can call the medical oncologist, they can call their surgeon, they can call their GP. There's a variety of ways... again, it's very, I think, intimidating for patients, because they don't know how to approach the problem that they have." (Healthcare Provider 6)</p> <p>"My first oral surgeon said "So now that we have a diagnosis, I sent this to the Tom Baker Center. The Tom Baker Cancer Center will be in touch with you." And as you can imagine, when you get diagnosed with cancer, all you think about is "What is the plan? What is the plan? What is the plan?" I never got contacted and I couldn't contact them... I had no idea who I could call if I didn't hear anything" (Patient Participant 7)</p>
	Disrupted continuity of HNC care	<p>"I think at a higher level, and this doesn't just apply to our service, it has been so well documented in Alberta and Canada, healthcare is incredibly siloed. Every group, whether it's radiation oncology or surgery or the nurses or the dieticians or rehab medicine, all have their own budget silo and managers. And it's very difficult to coordinate things between those silos, we've worked really hard at it. But there's no person at AHS (Alberta Health Services) that I am aware of in the mid-level executive position that can look at the whole program of care... So it is a major high-level system problem that prevents Canadian healthcare from being better." (Healthcare Provider 4)</p> <p>"If I have a radiation question, I have to go to the radiation oncologist's office. If I have a head and neck question, I got to go to that office, et cetera, et cetera. And that's okay except that like I said earlier, I don't think they [the healthcare providers] are all communicating. So somehow it [medical information] needs to get communicated." (Patient Participant 1)</p> <p>"I didn't understand why a hospital that takes me eight minutes to drive to and park and walk into, eight minutes away, I can't access. Yet to go see my oncologist takes me up to four and a half hours in my day." And to me, I'm going, "This is not in the patient's best interest." (Patient Participant 4)</p>

**Table 6** (continued)

Theme	Subtheme	Exemplar Quotes
	Healthcare system pressures	<p>"The psychologist that I saw at the Tom Baker Centre talked to me when I was there, and enrolled me in a cancer support group, which was, at that point, a Zoom meeting instead of a regular monthly in-person meeting. After I finished treatment, I continued with that up until this month. The psychologist retired in April and there is nobody to lead the group right now. It's a real shame because it's been a really helpful resource." (Patient Participant 10)</p> <p>"I am not their family doctor; I am their specialist. But not infrequently patients do not have a family doctor and/or have some issue with their family doctor, whether rightfully or wrongfully. I mean, yesterday somebody asked me to check their blood pressure, and we checked them, and it is high, but I said on an ongoing basis I am not going to manage this, especially since that person was well. If your blood pressure's high because of a problem related to your cancer, sure I will fix it, but if your cancer's fine and your blood pressure's an issue I expect you to see your family doctor about that. Last week I got a phone call to do a pap smear. I mean it is so hard to find a family doctor right now in Calgary, but I do not want to become their family doctor... I remember as a trainee thinking, "Why can't you do that? That's easy." But I had one mentor explain it to me and he said just as I told you earlier, that if I start managing everybody's blood pressure, and hypertension, I will not have time to deal with their cancer. So, I was like, 'Oh, that's a very good way of explaining it.' But that does not sound very nice to patients. I am selective. Some people do not have a family doctor, so it does not hurt me to prescribe a blood pressure pill." (Healthcare Provider 5)</p>
Relational HNC care	Patient Expectations during TiC	<p>"I did not know if anything [physical side effects] that was happening with me was normal, or what to expect. Not having anybody actively following me saying "How are you doing?" and "Yes this is normal" ... Tell patients what to expect after treatment is finished." (Patient Participant 10)</p> <p>"I have heard from patients historically anyways that when they come to the end of active treatment and they enter the phase of recovery and survivorship, they feel abandoned. I think it's because they are going through this intense treatment and it's the most difficult thing they've ever gone through, but at the same time, they are part of this membership where you're being seen every day by about ten people and any questions or difficulties along the way it's easy to just ask somebody. Once that's done, it's almost this anticlimax where they are not sure what to do with their day. They're left with the morbidity and toxicity of the treatment and it's a major hurdle to get over that, but they don't have the same interaction with the healthcare team that they're used to." (Healthcare Provider 1)</p>
	Feeling valued as a HNC patient	<p>"It just comes down to the care and compassion that you receive from people including the surgeons and radiation technicians. People like that, that genuinely care. When you're not well and you're worried about everything, those are beacons of light that give you hope that you will get through this." (Patient Participant 9)</p> <p>"I like seeing them [my HNC surgeons] every three months. It makes me feel safe." (Patient Participant 2)</p> <p>"I've talked to other patients who have a relationship with their oncologist, and I have to say, I have no relationship with my oncologist. I feel like I'm floating from person to person to person. I've only seen one fellow. They call them two times. Everyone else, it's always been a different resident, so for me, that feels troublesome." (Patient Participant 5)</p> <p>"Well, when I did chemo and radiation, I was surprised when I wondered what the follow-up was after that, that there was nobody to talk to. I wanted to ask the oncologist what happens next. I was told, no, that's not how it goes. He doesn't want to see you again. That seemed a little harsh. Whom do I ask? What happens now? And there was nobody to ask that to. His office was just a closed door." (Patient Participant 10)</p>



**Table 6** (continued)

Theme	Subtheme	Exemplar Quotes
	Healthcare provider roles and responsibilities	<p>"I think if an oncologist is going to keep referring you back to a General Practitioner, then the Oncologist and General Practitioner should have a conversation at one point, and discuss a plan together, and say, "This is what my response would be, this is what I need you to follow up with." And have that communication stream going, because it makes no sense to tell a patient, "Go see your GP," and you go see your GP, and they go, "I don't know what this drug is doing to you. I've never dealt with this drug before... To me, there's a big break in the system somewhere. Either have a general practitioner on your team that's trained within the Tom Baker, that you go see that person if you're experiencing things, but just to say, "Go back to your general practitioner and discuss this," made no sense to me." (Patient Participant 4)</p> <p>"When I went to the cancer center, I originally met with the oncologist who was the surgeon who originally did surgery on me. I saw them one time after the surgery to tell me what the result was. After that, every subsequent appointment I had was not with them. It was with either a different fellow or a resident, whoever was in the rotation at that point. There was some confusion on my part because I understood that I would because their name is on each of the written appointments that you get, so I guess I was so naive. I thought that I would be seeing her each time. You don't see that her every time. In fact, because they are a surgeon, you don't see them. You just see whomever the resident is. That was a bit of a shock for me that although I guess, they were behind the scenes reviewing the documents, but it never was the same person that saw you each time you went there." (Patient Participant 5)</p>
System and individual impact of TiC in HNC	Impact of resource-intensive nature of TiC	<p>"There is a lot of thought and effort that goes towards transitions, you know everything from simple things like reviewing all the information whether it's on paper or imaging when I first see a patient on the other end and making sure I have prepared all the proper transition documentation and notation and spoken to the relevant people who are then going to continue to look after the patient. In a sense, there is the written work and then all the meetings that take place to make sure, you know we have weekly meetings to discuss patients that are admitted to the hospital. A huge part of that is discussing transitions because essentially what we are doing is planning what it is going to look like when a patient is going to be discharged home. And then we have weekly meetings at the cancer center separate from that where we discuss a long list of patients who are essentially transitioning from one treatment to another and decide what that next step of treatment looks like and who is going to start looking after those patients. It is a big part of what I do... so it affects my workload, in the sense that I dedicate a concrete amount of time to both receiving and then transitioning a patient to another service or another location. And I have never actually tried to quantify that would be difficult because it is somewhat integrated into everything that I do." (Healthcare Provider 1)</p> <p>"The poor transitions are when you get the phone call from the emergency department in Lethbridge about a patient... and they have been decompensating since they left Tom Baker, those are the ones that are difficult to deal with, and they cause more stress." (Healthcare Provider 6)</p> <p>"If I anticipate that a certain individual is going to have a poor transition, I might do more follow-up appointments with them, or get my allied health professionals that are involved to touch base with them more frequently. It increases everybody's workload if it is a concern." (Healthcare Provider 6)</p> <p>"I would think from my point of view in my practice, the biggest challenges are resources including my own time. And the fact that we do work so hard at moving people through the system efficiently and that we do a ton of technically unpaid work to make that happen." (Healthcare Provider 4)</p>

**Table 6** (continued)

Theme	Subtheme	Exemplar Quotes
	Impact of TiC on quality of care	<p>“The HNC surgeon said, “You have squamous cell carcinoma. Absolutely, you are for sure going to have surgery, that we know. And most people with that have a glossectomy can still communicate.” And I was like, “Communicate? What does that mean?” And I said, “Will I be able to talk?” And he [The HNC surgeon] said, “Well, most can still communicate fairly well.” And I looked at him and I will always remember this, I said, “You know what I do for a living, right?” And he said, “I don’t think you need to worry about work right now. I think you should just let them know that you are going to need a lot of time off.” (Patient Participant 7)</p> <p>“The only thing healthcare professionals need to be mindful of is that we are human beings with feelings. I know that for them, you cannot become seriously emotionally involved or attached or anything, but I think it is necessary that people are mindful of the fact that the person who is laying in the bed with a can- nula in their throat and cannot talk has real feelings and emotion.” (Patient Participant 9)</p> <p>“People are aware of the problems with transitions in care, but they do not go to bed at night thinking about this or wake up in the morning thinking about this. It is not first and foremost. I mean, they are thinking more about waiting times. They are thinking more about access to care. They are thinking more about getting people into the treatment system and a problem like this is one of those, I think, relatively hidden problems. If you ask any provider about it or patients about it, this drives patients crazy. I do not think people are lying awake at night worried about this, which is a problem. You’ve got to have a willingness in your provider and patient group to tackle this as a problem [TiC] and so one of the first things one needs to do is to communicate with everybody that this is a prob- lem, that it is harming people and it’s costing us money and it’s inefficient and we could be a lot better.” (Healthcare Provider 2)</p>

providers exhibited compassion and empathy. Patients valued long-lasting patient-provider relationships, which extended beyond a specific episode of care, creating an enduring continuum of support. While an abundance of patients experienced strong patient-provider relationships, some patients had weak patient-provider relationships, where the relationship lacked trust, communication and collaboration leaving patients feeling unsupported and abandoned. These weak patient-provider relationships triggered patients to transition to other healthcare providers more frequently. Patients with HNC proposed that further involvement in the decision-making process would help make them feel valued. They expressed a desire to have their opinions heard, particularly when it came to decisions that governed their care during TiC.

**Healthcare provider roles and responsibilities**

Patients with HNC and healthcare providers acknowledged that there is a lack of clarity about the specific roles and responsibilities of each healthcare provider caring for patients with HNC. This lack of clarity was especially endorsed by patients. Patients found understanding who was responsible for specific aspects of their cancer care

(usually by oncologists) and non-cancer related care (usually by general practitioners) confusing which led to challenges in deciding who to consult about their concerns, with the general practitioners and oncologists often redirecting the patient to each other. To add to this confusion, the addition of medical residents and fellows to the patients with HNC’s care team was described as confusing and disruptive.

**System and individual impact of transitions in care**

Patients and providers experienced TiC differently during the cancer continuum. Healthcare providers perceived TiC as contributing to increased workloads and emotional distress, while patients with HNC associated TiC with decreased quality of care due to ineffective care and lack of patient-centeredness.

**Impact of resource-intensive nature of transitions in care**

Healthcare providers perceived the volume of tasks associated with TiC contributed to the burden on healthcare providers and patients with HNC. Many healthcare providers noted that high-quality TiC demanded significant time and effort to do well (transfer information between providers). Additional challenges related to ensuring a high-quality TiC included, adapting to evolving electronic

health record systems and collaborating with patients and colleagues. The extensive documentation required during TiC also created time constraints for healthcare providers, preventing them from spending adequate time with each patient. The introduction of a new electronic medical records system in Alberta further compounded this issue, with surgeons and oncologists describing difficulties in understanding and utilizing the system when transferring a patient's care, potentially resulting in insufficient information for the healthcare provider the patient is transitioning to. Additionally, healthcare providers noted that the additional responsibilities associated with TiC led to heightened stress levels and emotional repercussions due to witnessing their patients deteriorate after experiencing poor TiC. Although the resource-intensive nature of TiC was commonly discussed by healthcare providers, patients with HNC also described instances where they had to dedicate significant time and effort to organize their care, facilitate communication between healthcare providers and access information during TiC. A widely endorsed solution by both patients with HNC and their healthcare providers to improve TiC was the introduction of a care coordinator or patient navigator envisioning it as a strategy to improve TiC.

#### ***Impact of transitions in care on quality of care***

The opinions of patients with HNC and their healthcare providers diverged when discussing the factors that influenced the quality of care throughout the cancer continuum. Patients highlighted areas that needed improvement such as effectiveness and patient-centeredness. Ineffective care occurred when healthcare providers (especially primary care providers and dentists) failed to provide the appropriate care or identify symptoms as potential cancer resulting in prolonged diagnosis. A lack of patient-centeredness was noted by patients when healthcare providers did not take the time to understand them holistically, resulting in healthcare that was not customized around a patient's needs, characteristics and preferences. In contrast, healthcare providers focussed on the broader healthcare system barriers including budgetary constraints and a lack of awareness about TiC. Healthcare providers believed that the allocated operating budgets were constrained, which prevented the optimization of HNC care within the healthcare system. Additionally, healthcare providers emphasized the lack of awareness about TiC and their consequences for patient outcomes and healthcare expenditure.

#### **Discussion**

This multimethod study quantified the large number and variety of types of TiC patients with HNC encounter during their care; patients with HNC had an especially high number of emergency department visits, hospital

admissions and visits to general practitioners. The high number of TiC was described as a source of distress by patients and providers.

The findings of this study are consistent with evidence showing that patients with cancer use a high amount of healthcare resources. Studies have found that patients with cancer account for 10.5% of hospital admissions and patients with lung and colorectal cancer have, on average, 3.3 hospital admissions (Sauro K: Transitions in care among patients with lung, bladder, colorectal and head and neck cancer: A retrospective cohort study, In preparation). Similarly, in the present study patients had, on average, 7.8 emergency department visits during the study period, which may be higher compared to other oncological patient populations with a median number of emergency department visits of 2.0 over 4 years [49]. The differences in estimates between the present study and previous work may be partly explained by differences in patient populations and the objectives of each study. Similarly, consistent with our findings that patients with HNC consult many physicians, previous work found that patients with cancer see a median of 32 different physicians during their cancer journey [50]. Unfortunately, each TiC represents an opportunity for the occurrence of medical errors, adverse events, increased mortality risk, low patient satisfaction, elevated emergency department visits and poor quality of care [51–56]. Poor quality of care can stem from challenges reported in this study such as fragmented care, resource limitations and communication breakdowns between patients and healthcare providers. Patients with HNC in this study also emphasized the importance of patient-centeredness which are pillars of quality of care, and mirror findings in other oncology patient populations [57–60], where it has been reported that preferences, values, and needs are not adequately considered in their care [57, 58, 61].

As healthcare providers play a pivotal role in delivering care, factors such as physician wellness and burnout have been associated with poor quality of care [62, 63]. Oncology ranks as a highly stressful specialty compared to other healthcare specialties (internal medicine, neurology, and cardiology), leading to higher healthcare provider burnout rates [64, 65]. This elevated burnout can also be attributed to electronic health records usage, high workloads, and emotional distress resulting from long hours, high work intensity, time constraints and under-resourced work environments [63, 66–69]. Our findings illustrate a need to develop and implement tailored interventions prioritizing quality of care and alleviating healthcare provider burnout. Addressing the challenges identified by patients with HNC and their healthcare providers can help bridge the quality-of-care gaps within HNC care.

While the present study found a high number of TiC among patients with HNC, some of these transitions are appropriate and necessary to provide high-quality,

evidence-based care. While minimizing the TiC can decrease the risk associated with these vulnerable points in cancer care, another approach, which acknowledges the importance and necessity of TiC is to develop interventions to improve TiC. While some of the patient suggested strategies are innovative and understudied (consolidating HNC care), others have been shown to be effective at improving the quality of care during TiC [70, 71]. Shared decision-making (patients and their healthcare providers jointly making informed treatment decisions) [72], reduces decision conflict, sets accurate expectations, and aligns with patient values [73, 74]. Telehealth (the process of facilitating or delivering health services through any form of digital or telecommunication) [75], can improve TiC (reduce preventable hospital admissions) by fostering better multidisciplinary communication, strengthening the patient-provider relationship, and mitigating the impact of healthcare-provider shortages [76–79]. However, telehealth may not be feasible among a patient population whose ability to hear and speak can be significantly compromised. The implementation of patient navigators within HNC care was the most widely endorsed strategy. Patient navigators are dedicated members of the multidisciplinary team who are liaisons and advocates internally and externally within the healthcare system [80]. This strategy can alleviate some of the concerns expressed by patients with HNC in our study: enhancing continuity of care, providing more information, connecting patients with the most appropriate healthcare provider, and ultimately mitigating the difficulties they face when navigating the healthcare system [81, 82]. Additionally, this resource can ease the strain on healthcare providers by providing patients additional support, therefore, reducing burnout rates, minimizing the occurrence of medical errors and preventing turnover among healthcare providers [83]. In oncology, patient navigators have decreased hospital admissions, optimized resource consumption, increased quality of life and improved patient outcomes, among other benefits [84, 85]. Implementing a feasible and effective intervention such as patient navigators within HNC care can address challenges faced by patients and their healthcare providers during TiC. Future research should investigate the effectiveness of these strategies within HNC care, especially impacts on patient outcomes, provider well-being and the overall healthcare system.

### Limitations

This multimethod study integrated both quantitative and qualitative methodology, which generated a rich understanding of TiC among patients with HNC, enhancing the strengths of each method and mitigating their

respective weaknesses. In the retrospective cohort study, we were limited to the recorded information and existing variables in the databases used in this study, thus limiting the TiC we could explore. There were also limitations to the qualitative component of this work. Our included patient population is mostly female which does not reflect the general demographic of patients with HNC who is mostly male. This may be attributed to women being more inclined to seek medical attention, visit healthcare facilities and participate in research. Therefore, the perspectives of patients with HNC in our study may be less transferable to other populations of patients with HNC. Potential mitigation strategies for recruitment difficulties could be to partner with additional patient advocacy groups and offer tailored participation incentives for patients.

### Conclusions

In conclusion, this study identified a myriad of challenges faced by both patients with HNC and healthcare providers amidst frequent TiC. Our findings suggest that TiC can impact the quality of care and provide crucial insights that can inform and guide future research or the development of health interventions aiming to improve TiC within this patient population. These findings also identified potentially feasible interventions for further exploration, such as shared decision-making, telehealth, or a patient navigator within HNC care.

### Abbreviations

HNC	Head and Neck Cancers
TiC	Transitions in Care
HREBA	Health Research Ethics Board of Alberta
AHS	Alberta Health Services
STROBE	STrengthening the Reporting of Observational Studies in Epidemiology
RECORD	REporting of studies Conducted using Observational Routinely-collected Data
ACR	Alberta Cancer Registry
DAD	Discharge Abstract Database
NACRS	National Ambulatory Care Reporting System

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12885-024-12862-x>.

Supplementary Material 1

Supplementary Material 2

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Not applicable.

### Authors' contributions

J.K made substantial contributions to the conceptualization of the study, data collection, interpretation of the data, writing the original draft, and reviewing and editing the original draft. K.M.S made substantial contributions to funding acquisition, conceptualization of the study, data collection, interpretation of the data, drafting, revising the original draft, and reviewing and editing the original draft. S.C, P.R, P.R and J.D made substantial contributions to reviewing

and editing the original draft. All authors reviewed and critically revised the article and approved the version to be published and agree to be accountable for all aspects of the work.

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### Availability of data and materials

Data will be made available upon reasonable request to the corresponding author.

### Declarations

#### Ethics approval and consent to participate

This multimethod study was approved by the University of Calgary Health Research Ethics Board of Alberta (HREBA.CC-20-0474). A waiver of consent was granted for the use of the data from the administrative health databases for this study. The Health Research Ethics Board of Alberta grants a waiver of consent provided that the research meets the following criteria: (1) The research involves minimal risk to the participants (2) waiver of consent will not adversely affect the rights and well-being of the participants (3) The research could not be completed without altering the informed consent procedure (4) The proposed alteration is extensively defined and (5) The participants will be given any relevant additional information after participation whenever appropriate.

#### Consent for publication

Explicit consent was received from all participants to audio record the semi-structured interviews and to use anonymized quotations in research publications and dissemination.

#### Competing interests

The authors declare no competing interests.

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