


ORIGINAL ARTICLE

A qualitative exploration of the facilitators and barriers to early diagnosis and treatment of head and neck cancer: Perceptions of patients and carers

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Abstract

Objective: The objective of this study to explore experiences of patients and carers of the pathway to diagnosis and treatment of head and neck cancer (HNC), focusing on differences based on remoteness of residence.

Methods: Patients ≥ 6 months post-treatment completion, and their carers, were recruited. Semi-structured interviews, guided by the Model of Pathways to Treatment as the theoretical framework, were conducted to examine pathways to treatment of HNC and facilitators and barriers to early diagnosis and treatment. Thematic analysis with an iterative and data-driven approach was used to identify themes.

Results: A total of 39 patients and 17 carers participated in the interviews. Facilitators of timely diagnosis and treatment included a sense of urgency from health care professionals (HCPs), advocacy by the HCP or carers, and leveraging social capital. Distance to services, financial costs, and a perceived lack of emotional investment by HCPs arose as barriers to timely diagnosis and treatment. Participants were often able to rationalise that not all delays were negative, depending causes and expected impact on cancer management.

Conclusion: The findings highlight the complex nature of factors facilitating and impeding early HNC diagnosis and treatment that may be targeted in interventions to support patients and meet important benchmarks for high-quality cancer care.

KEYWORDS

access to healthcare, cancer, health seeking, lived experience, qualitative, remote/rural healthcare

1 | BACKGROUND

Early cancer diagnosis and timely commencement of quality treatment confer the best survival prospects and are central components to several national and international cancer control policies.

(Neal, 2009; World Health Organisation, 2017) In Australia, there are known 'rural-urban' disparities in outcomes for several cancer types (Stanbury et al., 2016a; Stanbury et al., 2016b; Tervonen et al., 2017; Venchiarutti et al., 2020; Yu et al., 2017), with increasing remoteness of residence generally associated with greater risk of advanced or

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unknown stage at diagnosis and poorer survival outcomes. Delays in diagnosis and treatment of cancer may result in advanced disease, more aggressive and morbid treatment, poorer oncological outcomes, worse quality of life caused by treatment sequelae that may persist for years, if not permanently, after treatment completion, and in extreme cases result in incurable disease from the outset. Epidemiological studies are underway to determine whether international differences in survival outcomes may be explained by variations in pathways to diagnosis and treatment of cancer (Weller et al., 2016), and sub-studies conducted in Australia have found that rural patients with colorectal cancer experience greater time from symptom onset to treatment compared to urban patients (Bergin et al., 2018), though breast cancer patients did not demonstrate these patterns.

Head and neck cancer (HNC) is a relatively uncommon cancer in Australia, accounting for 3.1% of new cancer diagnoses in 2018 (Cancer Australia, 2018). Though 5-year survival rates have improved to 70% between 2009 and 2013 (Cancer Australia, 2018), 56% and 13% of cases are diagnosed as advanced and unknown stage, respectively (Cancer Institute of NSW, 2022), and patients in regional and remote Australia have a greater risk of advanced or unknown stage of disease compared to their metropolitan (urban) counterparts (Jong et al., 2004). Reasons for this variation are unclear but likely include patient, health system, and disease factors (Walter et al., 2012) such as poor symptom appraisal and help-seeking by patients, insufficient access to and investigation in primary care, delayed referral to specialists for definitive treatment or poor communication between treating sites for regional patients treated at multiple centres. One study has examined pathways to diagnosis and treatment of HNC prospectively in Australia (Tan et al., 2016), finding that patients in remote North Queensland had longer times to diagnosis and treatment compared to regional patients; however this study is limited in its generalisability as metropolitan patients were not included. A recent study of patients in New South Wales (NSW), Australia, demonstrated that regional patients with oral cavity and oropharyngeal cancer have longer times to diagnosis and treatment compared to metropolitan counterparts (Venchiarutti et al., 2020).

Theoretical frameworks provide systematic approaches to explore health behaviours and decisions that influence the pathway to cancer diagnosis and treatment. The Model of Pathways to Treatment (Scott et al., 2013), a refinement of the General Model of Total Patient Delay (Andersen & Cacioppo, 1995), provides an framework that describes key events, processes and intervals that underpin the pathway to diagnosis of symptomatic cancer and has been influential in informing consensus statements about research into early cancer diagnosis such as the Aarhus statement (Weller et al., 2012). The Model of Pathways to treatment describes five key events: detection of bodily change(s), perception of reason(s) to discuss symptom with a healthcare practitioner (HCP), first consultation with HCP, diagnosis, and start of treatment. Four intervals are also described (appraisal, help-seeking, diagnostic, and pre-treatment), which define time between each of the five events, and four processes are defined that describe the 'cognitive, emotional, behavioural, organisational, or structural actions that occur within intervals'. Contributing factors, which are characteristics

of the patient, health system, and HCP that can influence processes, are also considered within the model. Understanding the how patient, health system and disease factors drive timely cancer diagnosis and treatment (Walter et al., 2012) can facilitate development of health policy that ensures equitable access to quality treatment. The aim of this study was to investigate the patient and carer perceptions of facilitators and barriers to early diagnosis of HNC, using the Model of Pathways to Treatment as a framework, with a focus on any differences based on remoteness of residence (metropolitan vs. regional/remote).

2 | METHODS

2.1 | Study design and setting

The study design was a qualitative interview study embedded within a prospective cohort study, in which participants were consecutively and prospectively recruited. The study was designed in line with the Aarhus Statement (Weller et al., 2012), an international consensus statement widely accepted as a framework by which to conduct early cancer diagnosis research. Participants were recruited from four HNC referral centres, one located in metropolitan NSW (Chris O'Brien Lifehouse/Royal Prince Alfred Hospital Head and Neck Cancer Service, Sydney) and three located in regional NSW (Mid North Coast Cancer Institute at Port Macquarie and Coffs Harbour, and the North Coast Cancer Institute at Lismore). NSW is the most populous state in Australia, with approximately 8 million residents as of June 2018, accounting for almost one third (32.0%) of the Australian population. (Australian Bureau of Statistics, 2018) Australia has a universal health system, in which patients have direct access to primary care practitioners who can initiate certain cancer investigations and refer patients to specialists for further management.

2.2 | Participants

Patients were eligible for participation if they were within 6 months of a new or recurrent diagnosis of HNC, were residents of NSW at diagnosis, and aged ≥ 18 years at diagnosis. Exclusion criteria for this study were haematopoietic malignancies of the head and neck region, patients with no fixed address, insufficient English to complete questionnaires and participate in semi-structured interviews, and cutaneous melanoma of the head and neck. Carers or family members of eligible patients were invited to participate.

2.3 | Consent

Patients and carers provided written consent for their contact details to be passed on to the study coordinator. Verbal consent was obtained for interviews to be audio-recorded.

2.4 | Ethics approval

Ethical approval was granted by the Sydney Local Health District (RPA Zone) Human Research Ethics Committee (Protocol No X17-0422 and HREC/17/RPAH/657), the Aboriginal Health and Medical Research Committee (AH&MRC) HREC (Reference No. 1370/180), and clinical governance was approved by each site.

2.5 | Data collection

Semi-structured interviews were conducted with patients and/or their carers who provided consent when previously completing the questionnaire investigating pathways to diagnosis and treatment of HNC. Given the focus on geographic differences in experiences in diagnosis and treatment of HNC, participants were given the opportunity to take part in the interviews either in person or by telephone (Novick, 2008) to ensure patients living at great distance from their treating hospital could participate in interviews. Interviews were conducted between April 2019 and May 2020 by Author 1 at the Royal Prince Alfred Hospital in Sydney. Majority of the interviews were conducted one to one; however, if the patient and their carer both consented to participate, they were able to conduct the interview in tandem. This occurred in 11 cases, and apart from the researchers and the interview participants, no other persons were present during the interviews. A semi-structured interview outline, which was developed by the study team, was used to guide the interviews. All participants were known to the interviewer prior to the interviews, as each participant had been recruited and enrolled into the research study by that interviewer. The interviewer had extensive knowledge of the Model of Pathways to Treatment and the Aarhus Statement from literature reviews.

Interview participants were purposively sampled from the main study cohort as part of a sampling frame based on sex, remoteness of residence (metropolitan or regional/remote), and time to treatment (time from symptom onset to treatment onset, dichotomised into ≤ 4 months and > 4 months). The decision to dichotomise patients' total interval was based on previous research where patients with oropharynx and oral cavity cancer were found to have a median total interval of 4.1 months (Venchiarutti et al., 2020). All participants provided informed consent and for the interview to be audio-recorded. The interviewer took field notes during the interview and completed a reflection log after completion of the interview. Interviews varied in length from 12 to 83 min (mean duration 34 min, SD 14 min), and no repeat interviews were conducted. Patients were asked to describe the pathway from recognition of first sign or symptom of the cancer to treatment of the cancer, with the interview probing on symptom recognition, healthcare seeking (in primary and secondary care), decisions on treatment modalities and place of treatment, and follow up care. To identify facilitators and barriers of early diagnosis and treatment, participants were asked to recall any delays they might have experienced, to describe any events or actions that may have led to delays and what actions were taken to overcome any

actual or potential delays. Following completion of the interview, all participants were asked whether they would like to review their transcript and if they did, were sent a de-identified copy of their own transcript for review, and any changes requested were documented. Interviews continued until data saturation (where no new themes arose).

2.6 | Data analysis

The theoretical framework used to organise the data was the Model of Pathways to Treatment, which describes the events, processes and intervals along the pathway to diagnosis and treatment of cancer (Scott et al., 2013). The framework defines four key intervals along the pathway to treatment: appraisal, help-seeking, diagnostic and pre-treatment. The analysis process used thematic analysis with an iterative and data-driven approach to identify major themes within the transcripts, with key stages guided by Bengtsson (Bengtsson, 2016). These stages are decontextualisation (familiarisation with the data and identification of meaning units), recontextualisation (cross-checking meaning units against the study aim), categorisation (identification of themes and sub-themes), and compilation (presentation of a summary of themes and sub-themes). Two authors (Authors 1 and 2) read through the transcripts to gain understanding and familiarity with the data. Beginning with a subset of the transcripts, meaning units (sections of original text) were identified from the transcribed interviews, which were then summarised into condensed meaning units, paraphrasing the original text without losing the meaning. The condensed meaning units were then given codes (no a priori codes were used), and during a group session, the authors compared codes, grouping them into categories of 'contributing factors' in reference to the Model of Pathways to Treatment. Differences were resolved by discussion. A coding framework was then generated for the dataset and all remaining transcripts were coded and entered into NVivo, with triangulation ensuring cross-checking of data sources. Author 1 defined and named the themes and mapped these to the Model using a concept map. The mapping of themes to the Model of Pathways to Treatment was reviewed, and quotations were extracted to support the analysis. Reporting of the methodology and findings is conducted in line with the COnsolidated criteria for REporting Qualitative studies (COREQ) guidelines (Tong et al., 2007).

3 | RESULTS

3.1 | Participant characteristics

A total of 97 patients were invited to participate in the interviews, of whom 64 indicated their interest on completion of the survey. Upon contact to arrange an interview, two declined (one due to emotional distress and one due to illness), four were unable to be contacted, and the remainder did not have an interview arranged due to data

saturation being reached. Table 1 describes the sample of patients ($n = 39$) and carers ($n = 17$) who participated in the qualitative interviews. Among patients, there was a mixture of primary tumour sites, two-thirds were from metropolitan areas and there were more males interviewed than females. Approximately half as many carers as patients were interviewed, and all but two were female. Eight of the 43 patients in this cohort were diagnosed with recurrent cancer—six with recurrent cutaneous cancer and two with recurrent thyroid cancer.

3.2 | Findings

Study findings are organised according to the four intervals described in the Model of Pathways to Treatment (Scott et al., 2013): the

TABLE 1 Demographic information about the patients and carers participating in semi-structured interviews

Characteristic	Patients (N = 39)	Carers (N = 17)
	N	N
Tumour site		
Cutaneous	12	1 ^a
Oropharynx	11	-
Oral cavity	6	3 ^a
Thyroid	5	-
Salivary gland	1	-
Larynx	1	-
Paranasal sinus	1	-
Osseous	1	-
Nasopharynx	1	-
Age group (years)		
21–30	1	2
31–40	1	2
41–50	5	2
51–60	7	5
61–70	11	5
71–80	11	1
81–90	3	-
Residence		
Metropolitan NSW	25	11
Regional/remote NSW	14	6
Sex		
Female	11	15
Male	28	2
Time to treatment		
≤4 months	20	-
>4 months	19	-

Abbreviation: NSW, New South Wales.

^aPrimary tumour site of the patient who did not complete the interview themselves.

appraisal, help-seeking, diagnostic, and pre-treatment intervals (Table 2). Within each of these intervals, key concepts illustrating facilitators and barriers to early diagnosis and treatment of head and neck cancer (HNC) from the experiences of patients and carers are presented, in addition to contributing factors that act as facilitators or barriers across more than one interval. See Table 2 for exemplar quotes within each framework interval and theme.

3.3 | Appraisal interval

3.3.1 | Previous experiences with symptoms

Patients contextualised symptoms they faced based on prior experiences in the healthcare system, which mediated the urgency of subsequent help-seeking actions. Patients experiencing symptoms they had previously encountered often normalised their symptoms or misattributed them to a benign condition. In contrast, patients who experienced a new symptom appraised their symptoms as more alarming or subjectively ‘not right’, leading to a decision to seek help more urgently in primary care. This appraisal response is consistent with the Common Sense Model of Illness Self-regulation (CSM) (Leventhal et al., 1980), which posits that upon detection of a bodily change an assessment is made by an individual based on its ‘expectedness’ and the degree to which it interferes with daily life, which influences the individual's subsequent actions, including more comprehensive appraisal (Scott et al., 2013), or transition to help-seeking.

3.3.2 | Overt changes in or persistence of the symptom

As put by Walter and colleagues, within the context of the CSM (Leventhal et al., 1980), coping refers to ‘behavioural reactions to changes to health threats’ (Scott et al., 2013), and coping methods changed as symptoms themselves evolved. A common trigger to seek help was either an overt change in, or persistence of the symptom despite previous coping mechanisms such as self-management. For example, one patient, who had noticed a lump in the mucosa of the lower lip, rationalised the lump as normal; however, a new numbness and tingling sensation in addition to the lump was the trigger for help-seeking, as this exceeded the ‘threshold of interference’ as suggested in the Model of Pathways to Treatment (Scott et al., 2013). Thus, a new coping mechanism (seeking medical help) was initiated. In other cases, an individual's social context influenced their self-regulation practices, which included someone other than the patient themselves who noticed changes in symptoms, which raised concern and prompted more urgent help-seeking. In one case, the partner of a patient later diagnosed with nasopharyngeal cancer noticed a change in snoring habit. Once this symptom became noticeable to another person, this triggered urgent help-seeking, demonstrating the importance of the social context in appraisal of symptoms.

TABLE 2 Key themes identified within each framework interval describing facilitators and barriers to early diagnosis and treatment of head and neck cancer with supporting quotations

Framework interval	Theme	Supporting quotations
1. Appraisal	A. Previous experiences with symptoms	<p>‘Yeah, I just had a sore tooth. I actually just thought it was ... one of my wisdom teeth just hurting me like they normally would’.</p> <p>[PT006, M, 31–40, metropolitan NSW, mucoepidermoid carcinoma of oral cavity, total interval 4.0 months]</p> <p>‘I would’ve made an appointment because it was quite a, a solid lump ... it was different to anything else that I experienced’.</p> <p>[PT065, M, 81–90 years, metropolitan NSW, metastatic cutaneous SCC, total interval 1.6 months]</p>
	B. Overt changes in or persistence of the symptom	<p>‘I started to get a numbness, a tingling sensation, um, into my, my chin and ... my lower lip which then made me think, well that’s not normal. [so] I thought I better go to my GP’.</p> <p>[PT013, M, 31–40 years, metropolitan NSW, mucosal melanoma of inner aspect of lip, total interval 12.0 months]</p> <p>‘The other thing was that, um, he had been snoring like he does not normally snore. But, um, so loud. I got to the point where, at times, I had to move rooms because the, the snoring was a, it was an issue. So, to me, the symptoms that, um, I mean PT004 would tell me that his ear was swollen but his snoring was unbelievable.’</p> <p>[CR004, M, 41–50 years, regional NSW, nasopharyngeal cancer, total interval 2.6 months]</p>
	C. Pre-cancer health-related behaviours	<p>‘And he very rarely whinged about anything. [he’s] just one of those people that just put[s] up with it and get[s] on with it, you know. And he’s never had a thing wrong with him in his life’.</p> <p>[CR083, M, 71–80 years, metro NSW, oropharyngeal cancer, total interval 10.4 months]</p> <p>‘He’s a farmer, he’s physically really tough. He will not fuss if he’s sick or hurt, he’ll come in and you’ll bandage him up ... and send him back out. So ... I know when he says, “this is not right”, I’ve gotta listen’.</p> <p>[CR012, M, 61–70 years, regional NSW, laryngeal cancer, total interval 10.4 months]</p>
2. Help-seeking	A. Availability of services	<p>‘Yeah, no ear, nose and throat specialist in our region ... is actually an issue for a lot of people. Yeah, there was one, but he retired, so this, yeah. And that, that GP thing, with it going through quickly and they are not getting to know their community’.</p> <p>[CR012, M, 61–70 years, regional NSW, laryngeal cancer, total interval 10.4 months]</p>
	B. Planned or opportunistic help-seeking	<p>‘But he [GP] was convenient. I would walk past [his practice] on the way to work. I’d be like, “oh, I’ll call in and get this sorted out.”’</p> <p>[PT034, M, 41–50 years, metropolitan NSW, paranasal sinus cancer, total interval 14.6 months]</p> <p>Interviewer: ‘And how long was it before you saw your GP?’</p> <p>Patient: ‘Uh, it was probably a month or so ‘cause I was running out of prescriptions, that’s the only reason I went’.</p> <p>[PT062, F, 71–80 years, metro NSW, cutaneous SCC, total interval 6.7 months]</p>
3. Diagnostic	A. Symptom appraisal and interpretation by the HCP	<p>‘[GP] had a look at it and said, “well, I do not like the look of that [lump], with your history of skin cancer. [You’d] better go and have an ultrasound.”’</p> <p>[PT121, M, 71–80, regional NSW, metastatic cutaneous SCC, total interval 0.8 months]</p> <p>‘I remember before I mentioned this lump in my throat to the doctor ... maybe four months earlier and he just flogged it off as if it wasn’t that important ... and there is a little thing in the back of my head that thinks ... it might not have been as bad if we got to it 12 months earlier’.</p> <p>[PT030, M, 51–60 years, metropolitan NSW, papillary thyroid cancer, total interval 15.7 months]</p> <p>‘... like thank goodness that pathologist continued. And they kept looking at my slides and they found a tiny, little, on the edge, poking out from under the inflammation, something that looked nasty’.</p> <p>[PT020, F, 41–50 years, metropolitan NSW, oral cavity cancer, total interval 7.7 months]</p>

(Continues)

TABLE 2 (Continued)

Framework interval	Theme	Supporting quotations
	B. Referral to a specialist after help-seeking in primary care	<p>‘[GP] also arranged for a consultation with a specialist very quickly. It was within two days of him saying he would do so, I had an appointment’.</p> <p>[PT033, M, 61–70 years, metro NSW, mucoepidermoid carcinoma of minor salivary gland, total interval 3.7 months]</p> <p>‘[HCP 1] sent mum to the wrong person. So, [HCP 2] automatically sent her to the right person ... she got diagnosed pretty much straight away once she got to the right professional’.</p> <p>[CR018, F, 81–90 years, metro NSW, high-grade dysplasia of oral cavity on background of recurrent oral cavity cancer, total interval <4 months]</p>
	C. Complex or unusual presentations	<p>‘Saying ... this does not make sense. They’re talking about melanoma and I had no visible signs externally. And ... there’s no reported cases of ... melanoma internally ... on the jaw’.</p> <p>[PT013, M, 31–40 years, metro NSW, mucosal melanoma of inner aspect of lip, total interval 12.0 months]</p> <p>‘... there was just uncertainty in interpreting the tests at each stage...And, I guess, we kept pushing’.</p> <p>[PT049, M, 51–60 years, metro NSW, oropharyngeal cancer, total interval 2.7 months]</p>
4. Pre-treatment	A. Complexity of treatment planning	<p>‘Yeah, and just, you know, little delays, like ... the screws [for the jaw reconstruction] got delayed because the plate ... was coming from Belgium and it did not arrive in time so I had to wait a week. And then the next time, um, I got delayed I think a week because the surgeons just ... They practiced, they took moulds of my bones and everything and they were practicing ... they just needed that extra week for more practice, I guess’.</p> <p>[PT020, F, 41–50 years, metropolitan NSW, oral cavity cancer, total interval 7.7 months]</p>
	B. Accommodation of services	<p>‘The issue with [hospital 1] was sort of that they were overloaded. And we did not know what they were doing specifically with that situation. We later found out that they then transferred the referral to [hospital 2]’.</p> <p>[CR004, M, 51–60 years, regional NSW, nasopharyngeal cancer, total interval 2.6 months]</p> <p>‘[I was asked] ‘are you privately insured. “Oh yes,” I said, “yes I am.” “well if that’s the case, we could fit you in [before Christmas]’.</p> <p>[CR121, M, 71–80 years, regional NSW, metastatic cutaneous SCC, total interval 0.8 months]</p>
	C. Services available in one location	<p>‘They understand each other, what they are trying to achieve together, because, you often have the appointment with both of them on the same day. Not together but, you know, so, they are sorta working together. So we felt more comfortable doing it there even though it was a lot more inconvenient’.</p> <p>[PT014, M, 61–70 years, regional NSW, oropharyngeal cancer, total interval 1.1 months]</p>
5. Common to several intervals	A. Leveraging social capital	<p>‘He called us back when I got home ... and said, “look. I’ve had a chat with the hospital. I’d like you guys to go up and, um, get a scan done.” so, I think, without that ... I do not think we would have got onto it as quickly as we did’.</p> <p>[CR004, M, 41–50 years, regional NSW, nasopharyngeal cancer, total interval 2.6 months]</p> <p>‘With those decisions that we had to make, through [CR022]’s contacts, we were able to bounce it off some other people who really were very highly-placed in the same field’.</p> <p>[PT022, M, 61–70 years, regional NSW, oropharyngeal cancer, total interval 2.9 months]</p>
	B. Sense of urgency conveyed by the HCP	<p>‘The ophthalmologist, who was on holiday, rang me in a panic and went, “You need to go to your GP immediately.” I’m like, “oh why? What’s wrong?” he goes, “There’s a huge tumour growing behind your eye. You need to get it sorted out immediately.”’</p> <p>[PT034, M, 41–50 years, metro NSW, paranasal sinus cancer, total interval 14.6 months]</p> <p>Patient: ‘Um, but the GP said it’s not urgent, um, and, uh, when ...’</p> <p>Carer: ‘That’s not how we acted’.</p> <p>[PT049, M, 51–60 years, metro NSW, oropharyngeal cancer, total interval 2.7 months]</p>

TABLE 2 (Continued)

Framework interval	Theme	Supporting quotations
	C. Emotional investment by and trust in the HCP	<p>'As far as me having surgery ... yeah, [there] was sort of speed too. Trying to nip it in the bud as quickly as we could'.</p> <p>[PT032, M, 21–30 years, regional NSW, rhabdomyosarcoma of mandible, total interval 7.8 months]</p> <p>'But then, once I saw [H + N surgeon 1] ... I mean he really inspired me with a lot of confidence. So once I saw him, I said, well, let us get it done'.</p> <p>[PT017, M, 71–80 years, regional NSW, oropharyngeal cancer, total interval 3.3 months]</p>
	D. Patient self-advocacy and being informed	<p>'Again, it probably comes back to that, that, what I was talking about earlier, that why did we wait six months? But I think for now it's like, "no, no. I want it to happen now." and maybe I'm being a little but too pushy but, you know, for me it's like no, no waiting. Let us go'.</p> <p>[PT013, M, 41–50 years, metro NSW, mucosal melanoma of oral cavity, total interval 12.0 months]</p>
	E. Travel or distance to services	<p>'... once, ah, [radiation oncologist 1], once [H + N surgeon] realised [where I was from], then it did become, you know, kind of obvious that coming down to, ah, [hospital 1] daily, was - was an impossibility'.</p> <p>[PT121, M, 71–80, regional NSW, metastatic cutaneous SCC, total interval 0.8 months]</p> <p>'We do not have access to a lot of specialists. We've got to travel. And that's, you know, understandable. But it was on our own bet that we'd go to Sydney. We were not averse to travelling down there'.</p> <p>[PT074, F, 51–60 years, regional NSW, thyroid cancer, total interval 3.9 months]</p> <p>'They essentially said to us, "look. We know you have come a long way. Um, we'll make sure that before you go home, um, we get this done." So, that was really good'.</p> <p>[CR004, M, 41–50 years, regional NSW, nasopharyngeal cancer, total interval 2.6 months]</p>
	F. Unexpected events	<p>'And then she was meant to have surgery earlier, but then she fell down 16 stairs and fractured her wrist. So, we left it for a week and then by that time they did the PET, [which] came back that there were met[astase]s on her lungs'.</p> <p>[CR069, F, 81–90 years, metro NSW, metastatic cutaneous SCC, total interval 2.2 months]</p>

3.3.3 | Pre-cancer health-related behaviours

Someone's typical health-related behaviours (which in the context of the CSM are 'coping' mechanisms) particularly with regard to symptom appraisal and help-seeking mediated the decision to proceed to the next step in the pathway. Male patients were often described as stoic by female partners or carers, putting up with a greater degree of discomfort before seeking help. Often in these cases, the social context (symptom appraisal by a partner or significant other) was the motivation for seeking help. Participants also revealed that for such patients, the decision to seek help reflected the perceived seriousness of the situation.

3.4 | Help-seeking interval

3.4.1 | Availability of services

As described in the Model of Pathways to Treatment (Scott et al., 2013), Social Cognitive Theory (SCT) (Bandura, 1986;

Bandura, 1997) underpins interpretation of the processes and contributing factors influencing behaviour in the help-seeking interval. In this context, self-efficacy describes an individual's perceived ability to discuss symptoms and get help, which may be influenced by personal characteristics as well as aspects such as the health system which they engage with. In this cohort, most of the perceived barriers to help-seeking were related to aspects of the health system, rather than personal barriers. Availability of services, which Penchansky and Thomas describe as the supply and demand of health services (Penchansky & Thomas, 1981), was the most commonly described barrier to help-seeking and was particularly evident from the perspective of regional/remote patients. These participants described difficulties in accessing help from general practitioners (GPs), but especially from specialists (head and neck surgeons, and ear, nose and throat [ENT] surgeons), as in many cases, there were no specialists practicing in their region. This necessitated long-distance travel and often long waiting times to see a specialist, which contributed to long help-seeking intervals. Availability of and distance to services are significant socio-structural barriers that exist for regional and remote Australians in accessing cancer care (Crawford-Williams et al., 2018; Goodwin et al., 2021), which

many participants in this study needed to overcome in order to be diagnosed and receive treatment for HNC.

3.4.2 | Planned or opportunistic help-seeking

Younger patients tended to make appointments with their healthcare provider (HCP) to specifically discuss their concerns regarding the symptoms they were experiencing. In one case, a patient sought help from a doctor out of convenience, who was not their usual GP. However, older patients were more opportunistic, often bringing up a concern while attending an appointment for another reason. These differences reflect socio-structural opportunities, as described in SCT, within the Australian healthcare setting in seeking help for cancer-related symptoms. Both pre-booked and 'walk-in' appointments are available in Australian general practices, giving patients the opportunity to expedite their help-seeking if the symptoms they experience exceed a threshold of interference. However, in patients who were more opportunistic in seeking help (by bringing up a symptom or concern during an appointment for another reason), this perhaps reflects outcome expectations—specifically social outcome expectancies. While a symptom might be bothersome and exceed an interference threshold, patients may be worried about wasting a HCP's time. Scott et al. (2009) have described patients with potentially malignant oral lesions waiting until more than one concern is present before seeking help. This action, which seeks to satisfy social expectancies, can be driven by fear that their concern is not legitimate or perception that they are a 'time waster' (Scott et al., 2013), which can lead to prolonged help-seeking intervals and potentially progression of disease.

3.5 | Diagnostic interval

3.5.1 | Symptom appraisal and interpretation by the HCP

Symptom appraisal by an HCP in the context of the patients' prior history facilitated rapid referral for investigations. One patient with a history of skin cancer described the high index of suspicion that his GP expressed upon presentation with a neck lump, which facilitated a faster referral to a specialist and diagnosis. During the interviews, discussion of events leading up to diagnosis often led to a reflection on the patient or carers part of inaction by an HCP. In most cases, patients considered the role of the HCP in a late diagnosis as critical, however were philosophical in attributing blame or responsibility of the late diagnosis. Patients praised proactive HCPs and those who pursued investigations based on 'gut feeling' of something more sinister. In one case, a pathologist continued to review biopsy specimens for signs of malignancy, despite an initial determination as no malignancy. These actions were considered key to obtaining a diagnosis, allowing the patient to enter the pre-treatment interval, and preventing additional delays and possibly progression of disease.

3.5.2 | Referral to a specialist after help-seeking in primary care

Patients seeking help from their GP more often reported a less convoluted pathway to the surgeon or oncologist ultimately involved in treating their cancer. This was often attributed to the existing relationships networks and GPs actions to facilitate a fast-track appointment. In contrast, patients who went through a dental pathway often experienced multiple referrals and a described a more circuitous pathway compared to those who initially saw their GP.

3.5.3 | Complex or unusual presentations

Complex or unusual presentations often precipitated a prolonged diagnostic interval. For example, a biopsy result indicating melanoma of the inner aspect of the lip resulted in diagnostic confusion and resulted in a lengthy diagnostic interval and ultimate referral for curative treatment. When investigations were inconclusive despite ongoing symptoms, patients saw this as a critical decision point where they could pursue further investigations. Some patients were relieved by a reassurance of no malignancy or a benign diagnosis and ceased further help-seeking until symptoms escalated or persisted. However, other patients and carers used their 'gut feeling' to pursue further investigations.

3.6 | Pre-treatment interval

3.6.1 | Complexity of treatment planning

Participants recognised the complexity of treatment planning as a source of delay in commencing treatment. This was particularly pertinent for surgical resections requiring reconstruction. These delays were reflected on positively by participants who considered them to be 'acceptable' delays in the scheme of the pathway.

3.6.2 | Accommodation of services

Accommodation of services, particularly for regional patients, manifested in the waiting times for appointments and treatment at local oncology centres, reflecting an important dimension of healthcare access defined by Penchansky and Thomas (1981). For one patient who resided between two regional oncology centres, their referral was transferred from one hospital to the other to accommodate the patient due to the potential for a delay in commencing treatment. For patients who underwent surgery, a major barrier to accommodation for surgery was financial. Patients who were able to pay through a private health fund found that they experienced short times to treatment after diagnosis. While patients on public waiting lists often had a longer wait compared to those who were privately insured or paying for the surgery themselves, often they were accommodated if needing

surgery urgently. This reduced the time waiting for treatment and reduced the financial burden of paying for surgery privately.

3.6.3 | Services available in one location

The benefits of having services and specialists available in one location were extolled by several participants, particularly patients who required multi-modal treatment. Patients in regional NSW often acknowledged the inconvenience of receiving all treatment, including radiotherapy, far from home but thought that the benefits of this outweighed the inconveniences. Acknowledging that their case was being handled by a multidisciplinary team in one location from the outset also reduced the impact on patients by mitigating the need to re-explain their case to several HCPs and undertake repeat investigations. This facilitated decision-making on the part of the treating team and mitigated the risk of a lengthy pre-treatment interval.

3.7 | Themes common to several intervals

3.7.1 | Leveraging social capital

Social capital refers to the way resources are organised and accessed from groups or networks that individuals belong to (Zhao et al., 2020) and is considered a key determinant of outcomes in healthcare. Social capital can include both cognitive and structural aspects (Kawachi, 2014) and, concerning cancer care, can refer to how individuals access diagnostic and treatment services, avail themselves of services to improve quality of care and experience of cancer treatment, as well as accessing social support to throughout the cancer pathway. Leveraging social capital to facilitate early diagnosis and treatment manifested itself in several ways and over the entire pathway. Particularly for the help-seeking interval, patients reported consulting with friends or family members in the health sector for advice on symptoms or help-seeking. Participants who had experience in the medical field also used social capital to become informed and seek reassurance from others regarding treatment choices.

3.7.2 | Sense of urgency conveyed by the HCP

How responsive and the degree to which a participant acted upon suggestions was very much grounded in the urgency displayed by the HCP. Participants acknowledged that the way in which this was conveyed needed to demonstrate an element of seriousness which the participant needed to take on, without causing undue psychological distress to the participant. According to the patients interviewed, if they perceived an HCP thought that a diagnostic error or patient safety was at risk (in the context of prolonged diagnostic intervals), the urgency was more pronounced. In some cases, participants described ways in which they used their own 'gut feeling' to override

the lack of urgency conveyed by their HCP, such as in the case of one patient who was told that an investigation should be conducted. In the context of the pre-treatment interval, having urgency conveyed to the patient made the decision process more definitive, resulting in a shorter pre-treatment interval.

3.7.3 | Emotional investment by and trust in the HCP

The extent to which patients perceived an emotional investment by the HCP emerged as important in both primary and secondary care. Patients recalled an increase in trust and confidence when HCPs were seen as invested in the patient outcome, and this manifested in more decisive actions by patients, contributing to shorter diagnostic and pre-treatment intervals.

3.7.4 | Patient self-advocacy and being informed

The experience of delays earlier in the pathway often changed behaviours later, which manifested itself as self-advocacy. One patient reflected on the difference in his attitude after experiencing a perceptibly long diagnostic interval, by describing his desire for more timely and decisive actions during the pre-treatment interval.

3.7.5 | Travel or distance to services

Travel and distance to services was a contributing factor in the help-seeking, diagnostic and pre-treatment intervals, especially for patients from regional NSW. Patients living in regional NSW often needed to travel to metropolitan NSW, where most specialists are located, to seek help and obtain a diagnosis, particularly when a second opinion was sought, either by the patient or GP. In some cases, this prolonged the diagnostic interval. Travel and distance to services also influenced the pre-treatment interval, as deciding where to be treated could impact timeliness of treatment. This was particularly evident when radiotherapy was required. Requiring daily treatments for up to 7 weeks, most metropolitan patients preferred radiotherapy treatment closer to home to mitigate travel required either by themselves or their carers, which in their case centred mostly on travel time rather than distance. However, this issue differed for regional patients. Regional patients who underwent surgery in metropolitan NSW (where most surgical services are located) and required post-operative radiotherapy fell into two groups—those who preferred to remain under the care of one centre and to remain in metropolitan NSW for the duration of their radiotherapy and those who preferred to undergo radiotherapy at a centre closer to home. For those who chose treatment closer to home, and therefore at a different institution, commencement of adjuvant therapy within optimal timeframes depended on coordination care by different cancer treatment centres, availability of radiotherapy treatment slots, and in some cases

pre-treatment assessment such as dental extractions or feeding tube placement, which could extend this interval. Patients living in regional NSW were aware and accepting of the need to travel for treatment and considered it a routine part of the help-seeking, diagnostic, and pre-treatment intervals, despite the inconvenience. These patients also noted that health services often accommodated them more readily, knowing that they undertook the additional burden of travel.

3.7.6 | Unexpected events

When patients and carers reflected on events along the pathway, some also recalled unexpected events completely outside their control or that of the medical profession that contributed to delayed help-seeking, diagnosis or commencement of treatment. In one case, events that lowered the priority of a cancer diagnosis results in progression of disease and alteration of treatment intent.

4 | DISCUSSION

This study provides insights into the facilitators and barriers to early diagnosis and treatment of HNC in NSW, Australia. Key facilitators identified by patients were the presence of alarm symptoms that either overtly changed or persisted despite management, the ability to leverage social capital to fast-track progress through the pathway, the sense of urgency imparted upon patients and carers by HCPs and accommodation of patients by health providers considering individual circumstances. When exploring the unique experiences of patients from regional/remote NSW, we identified that accommodation by health services was a significant facilitator, with health services often streamlining investigations or appointments to be held on the same day to prevent repeated lengthy travel. Key barriers identified by participants were the availability of services, diagnostically challenging cases, a perceived lack of emotional investment by HCPs, and appraisal and referral practices of HCPs. For patients in regional/remote NSW, lack of locally available HNC specialist services in these areas impacted on patient's ability to achieve timely help-seeking, diagnostic and pre-treatment intervals, though not necessarily as a rule. Acknowledging a systemic lack of specialist services locally, regional patients were aware of the need to travel to seek treatment, and many were willing to travel knowing that they would receive the best outcomes by travelling to major cities for management, without seeing this as an inconvenience. To overcome the barrier of distance, many regional patients opted to reach out to friends and family in major cities for support for accommodation or travel while staying in the city and were able to reach out to health services for streamlined appointments if needed. Metropolitan patients too experienced distance as a barrier, but in a different way. Travel time, rather than distance itself, was the primary barrier for metropolitan patients, particularly for those living on the outskirts of major cities. Interestingly, it seemed that metropolitan patients who had lengthy travel

times considered the travel a greater inconvenience than regional patients, likely because of regional patients' acknowledgement of the need to travel for specialist health services.

Events occurring in the diagnostic interval were often identified as causing delays in commencing treatment. Patients were insightful as to when and how delays occurred, identifying 'pinch-points' at which critical decisions or actions were made that in retrospect either prolonged or fast-tracked help-seeking or diagnosis. When considering responsibility for delays, participants were often philosophical about attributing direct blame to one person. For example, when discussing repeated visits for and management of symptoms that were considered benign, patients acknowledged that their outcomes may or may not have been different if they sought further investigation or a second opinion. We found that the degree to which a given factor acts as a facilitator or barrier, as well as how someone overcomes barriers, seems to be mediated by several patient factors. For example, a patient's age, remoteness of residence, and financial circumstances played into the ability to travel to seek help and access services. Interestingly, though participants mentioned the facilitatory nature of a HCP's 'gut feeling' (Pedersen et al., 2019; Smith et al., 2020), the feeling also arose through the interviews as present in patients and carers, which also acted to facilitate quick appraisal and early help-seeking. Several participants described experiencing something 'not right' that prompted them to seek help, while patients that appraised a symptom as normal or not out of the ordinary sought help with less urgency, leading to a longer appraisal interval.

We found that in line with previous research (Scott et al., 2013), symptom appraisal often acted as a key determinant of help-seeking and misattribution of symptoms could often lead to delay in diagnosis of cancer. This experience of 'normalising' symptoms has been noted in studies of several other cancer types such as ovarian (Evans et al., 2007), breast (Marlow et al., 2014), colorectal (Blackmore et al., 2020; Hall et al., 2015) and upper gastrointestinal cancers (Humphrys et al., 2020) and is consistent with the psychological theory underlying the Model of Pathways to Treatment (Scott et al., 2013). Andersen et al. (2010) noted how these actions relate to the concept of 'containment' proposed by sociologist Alonzo (1984), whereby interpretation of symptoms occurs within situational context that ultimately leads to a decision to seek help or not. The dimensions of access to healthcare proposed by Penchansky and Thomas (1981) arose frequently in the synthesis of the interviews to a different degree based on remoteness of residence. While all patients identified affordability, accommodation, and accessibility of services as considerations in how and where to seek management, patients in regional/remote NSW noted that availability (volume and type of existing services) as a barrier, but one that they were prepared to overcome.

Given the heterogeneous nature of HNC, future research may explore how and why a patient's pathway differs based on whom a patient seeks help from in the first instance. We secondarily found that patients who sought help initially from a dentist reported more circuitous pathways to a specialist and ultimate diagnosis, often requiring multiple referrals or visits to different HCPs. Though these

findings may not be generalisable, they align with those from Nieminen et al. (2018), who reported that patients who initially sought help from a dentist had longer mean primary healthcare intervals compared to those seeking help from a GP. Australian data (Kaing et al., 2016) show that initial management of oral cancer varies for general medical and general dental practitioners, and while time to presentation for oral cancer seems to be decreasing, the diagnostic interval has remained largely unchanged since the early 1990s. This may be due to difficulty understanding what the term HNC encompasses (with many anatomical sites and cancer types), the diversity of specialists who treat HNC (ENT, general, maxillofacial and plastic surgeons), and poorly defined oncology referral pathways for dentists, and so further research into these variations is warranted. To make it easier to get patients with suspected HNC to definitive care, referrals should be made to clinicians affiliated with a high-volume speciality head and neck multidisciplinary team, and for regional patients, someone who is also aligned with local services. Additionally, the eligibility criteria included patients with recurrent cancer, with the intention to explore pathways to treatment for patients with recurrent cancer separately to those with a new primary cancer. The proportion of patients with recurrent cancer was small (8/43 patients) and six of these patients had recurrent cutaneous cancers, which did not represent the heterogeneous tumour sites that characterises HNCs. Patients with recurrent cancer who were interviewed also did not indicate any experiences or contributing factors specific to having a recurrent cancer, potentially because the nature of cutaneous HNCs are such that patient appraisal, help-seeking, and diagnosis are fairly standardised, especially in Australia where skin cancers are common. For these reasons, the experiences of patients with recurrent cancers were not discussed separately, but a detailed exploration of experiences of patients with recurrent HNC is warranted.

4.1 | Clinical implications

The facilitators and barriers identified by participants in this study may be addressed by clinicians and policymakers in one of two ways. Though the lack of head and neck services in regional NSW is not a new finding, it is concerning that patients rarely reported accessing services that intend to overcome this barrier such as outreach clinics or telehealth services. A survey of ENT surgeons (Shein et al., 2019) in NSW and the Australian Capital Territory in 2016/17 found that one in five ENT surgeons provided an outreach service during the period 2012 to 2016, with a mean yearly commitment of 5.5 days, across 18 towns in NSW. This demonstrates that patients in regional and remote NSW are not receiving their share of ENT services, and it is likely so for head and neck surgical services. Telehealth may help to overcome this issue, but it also requires GPs to identify and refer patients appropriately, ensuring that patients have access to technology or services to utilise telehealth, as well as appropriate funding models to support long-term use of telehealth. Second, continued educational programmes aimed at the population as well as GPs and dentists may help to raise awareness of HNC symptoms and

ameliorate misattribution of symptoms, leading to longer help-seeking and diagnostic intervals. Educational sessions held by ENT/head and neck surgeons would help to raise awareness of HNC symptoms in primary care, as well as promote the use of outreach services in regional/remote areas of NSW.

4.2 | Study limitations

One of the limitations of this study is the potential for recall bias to have affected participant recollection of events during the interviews, which often took place months after diagnosis and treatment had occurred. At times, patients and carers gave different accounts of the same events, which may have reflected their different interpretation of discussions or decisions, or potentially, the fact of a cancer diagnosis may have changed how a participant recalled events and attributed symptoms. Though the interviewer attempted to ameliorate recall bias by cross-checking events with patient questionnaires and medical records, this still raises a concern as to the validity of the findings in the context of potential recall bias. The primary strength of this study is the diversity of participants. Participants were purposively sampled to ensure representation from metropolitan and regional NSW, male and female patients, and patients experiencing relatively long and short total intervals. In addition, we were able to include a diverse number of participants representing most of the 10 anatomical sites that encompass HNC. Additionally, the inclusion of carers as interview subjects added insight from a different, though not always objective perspective of someone who also experienced the pathway to cancer treatment.

5 | CONCLUSION

The findings of this study help to understand the reasons why a patient may delay seeking help for symptoms suggestive of HNC, and the health system factors that facilitate and impede early diagnosis and entry into the treatment pathway. Patients from metropolitan and regional/remote NSW appear to have similar pathways to diagnosis and treatment of HNC, with the main differences in the help-seeking, diagnostic, and pre-treatment intervals that are attributable to lower availability and accessibility of services in regional/remote NSW. These differences may explain differences in timeliness of the pathway to treatment of HNC for regional/remote patients, and the poorer cancer outcomes observed in these populations. Successful and timely progression through the pathway relies on patient's abilities to identify signs or symptoms as concerning and seeking help in primary care where the appropriate index of suspicion is applied by the HCP to diagnose and refer a patient for management.

ACKNOWLEDGEMENTS

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

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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How to cite this article: Venchiarutti, R. L., Pho, L., Clark, J. R., Palme, C. E., & Young, J. M. (2022). A qualitative exploration of the facilitators and barriers to early diagnosis and treatment of head and neck cancer: Perceptions of patients and carers. *European Journal of Cancer Care*, 31(6), e13718. <https://doi.org/10.1111/ecc.13718>