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### Cover Page Footnote

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# Patient experiences through head and neck cancer: Information delivery combatting psychological distress

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## Abstract

As part of a larger study investigating the utility of electronic decision support tools for patients with head and neck cancer (HNC), this article describes the patient experience of receiving cancer treatment in British Columbia, Canada. It aims to give voice to the patient experience and recommend a model of psychological adjustment for clinicians and clinical service management to consider to refine patient centric care pathways for HNC. Based in phenomenology, semi-structured interviews were conducted with 12 survivors of HNC, audio-video recorded, and thematically analyzed. Three themes were identified: (1) patients have high, though varying information needs; (2) an emotional experience; and (3) coping, strength, and resiliency. These themes arose from six concepts: (1) information needs; (2) fear of the unknown; (3) desire for personalized information; (4) varying degrees of information needs; (5) fear as a motivator versus stressor; and (6) high information needs on life after treatment. Conclusions: The patient experience must be considered through the full care trajectory and into survivorship to provide the right information to the correct patient at the optimal time. Patient journey mapping may be a novel approach to exploring the temporal relationship between information needs and the patient experience along the cancer continuum to uncover opportune moments, from the patient perspective, for knowledge and supportive care intervention. The model of psychological adjustment by Calver et al. (2019) can be considered to inform the delivery of cancer care information in a method recognizing the patient as the ultimate knowledge holder.

## Keywords

Patient experience, health literacy, information needs, head and neck cancer, patient-centered care, patient journey mapping

## Introduction

In 2022, it is estimated that 7,050 Canadians will be diagnosed with head and neck cancer (HNC) and of particular concern for its increasing incidence.<sup>1</sup> HNC is associated with high morbidity as treatment can cause an array of acute side effects including but not limited to pain, nausea, vomiting, fatigue, radiation dermatitis, and oral mucositis.<sup>2</sup> Some side effects such as xerostomia, dysphagia, and dysgeusia may never fully recover, diminishing long-term quality of life (QOL). While survival remains the primary outcome, special attention should be paid to the impact on QOL as these physical symptoms result in psychological distress. Even with successful treatment, physical and psychosocial complaints can persist.<sup>3</sup>

Providing sufficient cancer-related information to best meet patient information needs has been a targeted solution for reducing psychological distress. Applying a phenomenological approach, this article is a part of a larger objective of gathering feedback, through semi-

structured interviews, on the utility of an electronic decision support tool for patients with HNC. This paper aims to give voice to the patient experience by acknowledging cancer survivors as the ultimate knowledge holders, describe the experiences of survivors who underwent anti-cancer treatment, and recommend a model for clinicians and clinical service management to consider to refine patient centric care pathways. Understanding the patient experience has practical implications at a clinical level and is a way of ensuring care is truly patient-centred.<sup>4</sup>

## Methods

Review Ethic Board (REB) approval was granted January 18, 2021, from the University of Victoria Human REB (University of Victoria Study #BC20-0546) and UBC/BC Cancer Agency REB (H20-02307). All participants provided written informed consent prior to commencing the study.

**Table 1. Inclusion and exclusion criteria for semi-structured interview.**

Inclusion	Exclusion
<ul style="list-style-type: none"> <li>- Diagnosis of HNC (including nasopharyngeal) of any staging with completion of treatment (radiation and/or chemotherapy, with or without surgery)</li> <li>- Treatment completed within the previous 5 years</li> <li>- Resides on Vancouver Island or Gulf Islands</li> </ul>	<ul style="list-style-type: none"> <li>- Inability to communicate proficiently in English</li> <li>- Inability to meet via virtual platform</li> <li>- Participation discouraged by oncologist, psychiatrist, or other physician</li> </ul>

**Recruitment and Materials**

Recruitment was conducted through convenience and purposive sampling, with a target of 6-12 participants or until saturation reached.<sup>5</sup> Inclusion and exclusion criteria are described in Table 1. Upon consent, demographic, diagnosis and treatment plans were extracted from the electronic medical record.

**Interviews and Analysis**

Semi-structured interviews, including field notes and reflective questions,<sup>6</sup> were conducted following an interview guide (Appendix, Supplement A). Interviews were conducted through Zoom during the COVID-19 pandemic. All interviews were video-recorded, transcribed, then analyzed using Taguette software.<sup>7</sup> Reflexive thematic analysis was performed by two researchers on annotated transcripts, field notes, and reflections where an open and iterative process was applied to coding following the six step approach of Braun and Clarke.<sup>5</sup> Data validation was conducted by sharing preliminary themes with participants for correction, modification, or confirmation.

**Results**

**Demographics**

Twelve participants were interviewed from ages 34 to 76 years, with half (n=6) of participants diagnosed with stage III cancer and nearly half (42%) undergoing surgery prior to radiation. Seven participants (58%) were offered adjuvant chemotherapy, three accepted cisplatin and the remaining four declined chemotherapy. Most participants accessed the symptom management team on a regular basis (75%) and connected with a counsellor through treatment (83%) (Table 2).

**Themes**

Three themes were identified related to the patient experience: (1) patient have high, though varying information needs; (2) an emotional experience; and (3) coping, strength, and resiliency. These themes arose from six concepts: (1) information needs; (2) fear of the unknown; (3) desire for personalized information; (4) varying degrees of information needs; (5) fear as a motivator versus stressor; and (6) high info needs on life after treatment.

**Category 1: Patient Experience**

*Theme 1: Patients have high, though varying, information needs*

A third of participants (n=4) collected copies of their medical records, while several participants who did not access their records were unaware of the option.

*“No, I did not, and it didn’t even occur to me but that would have been very interesting. I don’t know why it didn’t occur to me.”*

Several participants did not feel there was a need to have their medical records as they felt *“very comfortable with [their oncologist] and [their] team. I never felt the need to delve further into my treatment. I felt it was going well.”* One participant commented that in retrospect it may have helpful:

*“Looking back on it, you realize that you’re trying to make large decisions that are going to affect your life on a few meetings with some very talented doctors and individuals who are well meaning but there’s just no way you can ask everything and there’s no way they can share everything. So it’s a good way to keep track of what’s come up and make notes about what you want to discuss next.”*

While those who did request records did so *“just so that [they] have a complete audit history on paper in [their] own personal possession that [they] can refer to.”* Another found *“things are sometimes missed or, and [they] found that by reading everything [them]self and questioning it, [they] can get the answers or get it, you know, taking a second look.”*

Participants described the degree and type of self-research they conducted. While nearly every participant conducted their own research in either preparation for treatment or during treatment, one participant preferred not to know the details of their diagnosis or prognosis, *“I avoided completely anything about my specific type of cancer or prognosis and I said to the doctors, ‘I don’t want to know any of that information.’”* Of those who did research, the type and extent ran the full gamete:

*“I just like went crazy looking at for information initially. I really scared myself until I got more of a diagnosis and then I calmed down a bit.”*

*“In preparation for treatment and then post-radiation. I certainly researched the side effects I was experiencing.”*

**Table 2. Participant demographics**

Characteristic	Frequency, n (%)
Sex	
Male	8 (67)
Female	4 (33)
Age	
30-40	1 (8)
40-50	2 (17)
50-60	3 (25)
60-70	2 (17)
70-80	4 (33)
Cancer staging*	
Stage I	2 (17)
Stage II	4 (33)
Stage III	6 (50)
Stage IV	
Treatment type	
Surgery	5 (42)
Radiation	12 (100)
Chemotherapy	3 (25)
Cisplatin	3 (25)
Cetuximab	0 (0)
Declined by participant	4 (33)
Degree of involvement with symptom management team (General Practitioner in Oncology and Registered Nurse)	
Less than once per week	3 (25)
Weekly	5 (42)
Greater than once per week	4 (33)
Degree of involvement with Patient and Family Counselling	
None	2 (17)
1-3 times through treatment	3 (25)
Greater than 3 times through treatment	7 (58)

\*Based on AJCC 8<sup>th</sup> edition <sup>8</sup>

*“I wasn’t made fully aware of how profound the effects would be. So I found myself googling everything and getting information online.”*

Multiple participants found comfort in seeking out information from family, fellow patients, and support staff:

*“I found the support group was the best place to get a real feel for what all the side effects could be.”*

*“My wife was a university professor and taught SLP and that kind of thing at [university]. And so, because I had a researcher living with me and she was able to come to see [my oncologist], we got to ask questions together and [they were] so patient.”*  
*“Without [my wife] there, I would have been lost.”*

*“I had much more reassurance and comfort speaking to the dietitian and the nurses. They just seem to make so much sense, they were dealing with the people, they hear all that stuff and whether it’s*

*documented I don’t care, it doesn’t matter, it don’t need to be scientific, someone saying ‘I talked to 10 people five of them said...’ but like ‘hello!’ It’s just amazing how that’s comforting.”*

*“Also kept in touch with a group of people who were carrying and praying for us.”*

One participant described the commodity shared with another cancer survivor who also had a similar reaction to radiation:

*“I went to a [supportive care cancer organization] before I started my treatment, when they were making the mask. And there was a woman there who I told my experience, it was like a meditation group, and it was in person in those days, and one woman spoke up and said, ‘I have the mask too.’”*

Two participants referenced a blog written by a survivor of HNC who underwent treatment at the same facility,

enjoying the details of the bloggers own journey and links to recent research articles.

Through these conversations, it became apparent that this group has high information needs, often beyond what was provided by their oncologist:

*“During my entire life, two and a half/ three-year cancer journey was the fact that I kind of felt just like I didn’t know what the heck was going on as far as adjusting to recovery reactions.”*

One participant described the panic that ensued when informational resources were not provided in a timely manner:

*“When you’re in the moment you’re in distress and you’re like, ‘I don’t know how I’m going to cope today with it’, and then you’re on the phone crying to the oncologist. It could all be avoided just simply by like a pamphlet or, you know, I found the materials were like really simple and, like ‘What year are we in here?’ How do we not have better resources that I could look at something and be like, okay, these are the side effects.”*

This mirrored the need for timely provision of information by another participant who stated, “I want to hear that ahead of time so that I can prepare myself.”

Several participants felt hesitant to ask too many questions as they were cognizant of their oncologists’ time:

*“I was nervous at the time to do it, but I would have asked more questions.”*

*“I’m sure I took notes [prior to my appointments] but when I would see [my oncologist] or [surgeon], I would make a list of things, but it wasn’t very, no fault of theirs, but it’s not very conversational, and you also feel like you don’t want to spend all this time talking.”*

It was also acknowledged that even though comprehensive information may have been provided on their diagnosis, treatment options, prognosis, and side effects, this verbal content did not “sink in” well at that time:

*“I maybe got a 10th at best of what they were saying.”*

*“I’d be wiping my face and just be like, nervous and, I just nod and agree and then [my partner] asked me afterwards [what was discussed], and I didn’t have a clue.”*

The participants who felt they had unmet information needs listed specific examples of content, such as skin damage, blistering, cognitive exhaustion, and that could have been better explained.

*“I kept asking for statistics on, well, people down the road. Like, what do they face? What do they look like? And the story you get is, ‘Well, everyone’s different, everyone has a different experience.’ ...*

*That is not an answer. When I’m asking you when you’ve been doing this for decades, and you can’t tell me and give me any kind of just ballpark information on what people are experiencing. I’m not looking for the best scientific research I’m looking for, you know, ‘60% of people age 60 to 65, two years old are experiencing these side effects.’”*

Two participants did not know what to expect during the mask-making:

*“I didn’t understand that [the radiation mask] was going to get hard on my face, and that I was going to also feel trapped and claustrophobic.”*

*“In my head I have no idea what [the radiation mask] looks like or do they sedate you? You know? Like there’s so much information that you can give about that.”*

Despite 75% of the participants feeling their information needs were not sufficiently met, a quarter of participants ( $n=3$ ) did feel they were provided adequate information prior and during treatment, in a well-received and compassionate manner:

*“I was also very lucky that right off the bat, I would repeatedly be told by [my oncologist] ‘It’s common, it’s treatable. We caught it early.’ So, I didn’t have much need to do a lot of research.”*

*“I think we feel looked after and I think we had the idea that we’d cross bridges when we came to them.”*

The amount of information individuals preferred to have upfront related to whether they saw fear as motivation or anxiety-inducing, “Lack of information causes more fear of what you’re going into, that’s probably the biggest thing, fear of the unknown.” While others felt having more information about side effects upfront “wouldn’t have changed [their] medical decisions, but it would have almost been too much information for [them], because then [they] would have been so nervous and staring at [their] mouth and holding up mirrors constantly. So in a sense for [them], personally, it was better than [they] didn’t know what was happening until recently.”

*“We found all through the treatment they often tend to give you the maximum effects and I sense that was deliberate. The thought was, I think, to warn people because that would put some people off and it would put me off.”*

### Theme 2: An emotional experience

The theme of emotion was the most recurrent theme throughout the interviews with approximately half of the interviews displaying physical emotion, most notably tears and anger. While several participants had a relatively positive experiences through treatment marked by pleasant emotion, such as a gratitude, the majority found diagnosis, treatment, and the healing phase to be an emotionally

trailing experience. Ten codes captured the most frequently elaborated emotions (Table 3).

Gratitude was the most frequently applied code related to emotion with every participant expressing gratitude either towards their care team, support systems, or for life:

*“Every single person was gentle, kind, and patient and those three things made it possible, without those three things I was going to walk out and give up.”*

*“[My Radiation Oncologist’s] so kind and wonderful I just loved and appreciate [them], very compassionate.”*

*“I can’t believe how positive it was.”*

*“My ability to go through [treatment] was completely hinged on the kindness of the counselors who came in [to radiation]. I would hold each of their hands until the last minute when one of them let go. One of the [Radiation Therapists] even made me like a rubber band.”*

*“I have this need to show people [my photo through treatment] then to show them how far I’ve come because I feel like it’s like this is miraculous for me! It’s like I’m really proud of it and I’m really, you know, very \*tearful\* I’m so grateful to my doctors and so grateful to*

*everyone at the Cancer Agency. I guess my wishes- if there’s someone who’s fearful or afraid was something similar. If my experience could help them if I could show them my photos and secondly, like that woman at the support group who said to me, you know, ‘Oh no, it’s going to be okay’ and this is, \*tearful\* I think that would be super helpful.”*

Along with gratitude was a sense an optimism shared amongst several participants:

*“I was like ‘Yeah, I’m super star! I’ll be fine! I’ll be okay!’ So I sort of didn’t worry too much hearing about all of [the side effects].”*

*“That’s the cool thing about it is that you can actually watch [my tumour] shrink before your eyes.”*

*“There are a variety of things that were great about the [Head and Neck] Support Group, but the fact that there were patients who had gone through everything. And now we’re on the road to recovery and seemingly doing well with that, that really gives everyone hope, so that was so it was very important for me, ahead of time to have that feedback.”*

**Table 3. Codes related to emotion**

Emotion	Number of tags (%)
Gratitude	61 (52.5)
Shock	34 (29)
Optimism	26 (22.4)
Fear	25 (21.5)
Disappointment	11(9)
Panic	10 (8.6)
Sadness	8 (6.8)
Enthusiasm	7(6)
Vulnerability	5 (4)
Depression	4 (3.4)
<b>TOTAL</b>	116
Emotion*	54
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TOTAL	116
Emotion*	54

\*Defined at displaying emotion during the conversation or referring to an emotion not captured in other tags.



Participants described feeling shocked by their reaction and their families' reactions the diagnosis, aspects of treatment, side effects, and communication with the care team:

*"During my treatment, and I talked to my [oncologist] and it literally was a phone conversation so I couldn't really hear [them] but [they] literally said [my symptom] couldn't be caused by [radiation]."*

*"I was totally blown away because even though I tried to do my own research I realized this is not addressing my question. And so then as my depression kept on and now, I'm in a funk- 'What the hell is going on?'"*

*"It just like, you know, your organization has been doing this for decades. And nobody knows [about this side effect]? Like you know I'm not complaining at you but it's just kind of shocking. It's, it's, like, shocking! So that's a polite way to say not acceptable."*

For some participants, this shock led to panic:

*"And I was also trying not to try to forget that I was being like bolted down and trapped, but it's like oh you're looking at your cage... basically trapped you, and that can lead to more panic."*

*"Those fears were coming back that I was going to be panicked."*

*"This [fibrotic mass] developed months later, I had a massage and the massager, they're like, 'Oh, this is really hard here.' I went home and felt it. You're like, totally panicked and was convinced that I had a tumor there, and that it was a lymph node or metastasis."*

For some, this sense of panic lingered and led to a chronic state of being overwhelmed:

*"I was pretty much overwhelmed every time I went to the hospital. I didn't know I was, but I was and I knew because I sweat through my shirt."*

*"So I sort of felt at times I was in a battle zone, these doctors had very strong opinions and I was trying to navigate that."  
"I freaked out."*

*"I was anxious."*

For some, the huge change in life led to depression:

*"There was really the down period, emotionally, after treatment ends when, you know, you're going day after day and you're seeing all these happy supportive faces and then suddenly that's over, and you're on your own..."*

Like depression, several participants expressed a sense of disappointment with the experience through treatment or the diminished QOL following treatment:

*"I just sort of felt that I wasn't getting a complete up-to-date picture, and that I was getting steered into the organization."*

*"There's no pleasure in food anymore for me. I just eat to not be hungry and, you know, get some nutrition, obviously, if I didn't have to eat I wouldn't eat. And every time I eat I always have the same thing I'm always like, 'Okay, this is going to be the one where, you know, it just tastes so amazing and I get to relive that experience where you're eating something and you just can't get enough of it. Love it! So good!' No-haven't had that yet."*

Fear of recurrence or worry of radiation field "missing a spot" was also described:

*[My Radiation Oncologist] knew I was so afraid of this whole thing."*

*"I'm so afraid. It was also another near-death experience. I was totally convinced this [lump] was [recurrent disease], and then I had to add, they actually brought the radiologist in to reassure me and say, 'This is just muscle, we're just seeing muscle here.'"*

Sadness was a subtle theme, not explicitly discussed, but captured in the tone and reflexive questions:

*"It's amazing how little capacity I had for convincing people that I was really feeling what I'm feeling. That was quite odd."*

*"So there were all these other implications for me that were that were difficult and painful."*

Tremendous vulnerability was demonstrated and described:

*"I'll just show you because I have my, I have my, my pictures ... but I mean like this was like, you know, this is kind of at the peak of the redness and blistering."*

*"I just feel vulnerable."*

Several participants described treatment as "a very traumatic experience" which, when coding, was differentiated from general emotion. The code, "traumatic" was applied 25 times, representing 25 distinct moments where a deeply disturbing experience was discussed.

*"After the trauma of [explicit side effects]... I go through all the trauma and then find out that potentially [chemotherapy] was a choice that I didn't have to do? Yeah, doesn't mean I wouldn't have done the chemo, but at least then I would have known that I was making a choice for myself."*

*"After about a week into treatment I got a sense of like, I would almost call it like post-traumatic stress shockers... it was a real sense of dread like even now when I go to drive back towards the Cancer Agency, I have that same feeling come over me."*

*"And so, I have to admit, probably for about six months I was in a state of shock that even though on the surface maybe people told me I*



*handled it very well. It took me about five or six months to sort of just calm down."*

*"I think for me what was most frustrating is it's not like a hotel with a dirty toilet. You know I can't get an upgrade to a better room or complimentary night. You know I just get to go home and be traumatized, and my family gets traumatized."*

Visual changes or side effects, such as eating difficulties, that could be noticed by others were frequently cited as having the largest of impact on quality of life and the participants sense of normalcy. The code "appearance" was tightly associated with the code "trauma."

*"Every time you look in the mirror you see it and it's a reminder."*

*"Skin damage elasticity of skin damage. Yeah, it was like, 'No, I wasn't told about that.'"*

One participant commented on how more reconstructive efforts seem to be placed on breast cancer than HNC, despite changes occurring on the face and/or neck—*"changes that are forever going to make [them] look different."* Several participants discussed the difficult trade-off between aesthetics and medical treatment.

*"[My surgeon said] 'I need your permission to take the nerve.' And so, I thought about it I'm like, you know, I'm not going to agree to permanently disable myself, you know, not that I'm vain but to be drooling to not be able to control it was a lot even consider."*

### Theme 3: Stories of coping, strength, and resiliency

Despite the challenges and emotion faced, stories of strength and resiliency were shared. Participants shared strategies they used in preparation for treatment and coping throughout, most frequently citing mindfulness and meditation.

*"I even did like visualization on the table. I actually, like, visualized a laser sort of destroying the cancer cells and I did mantra, like 'I'm well, I'm healthy' or whatever. Those kind of things, sort of those tools, allowed me to just drown out the stress of looking up at that machine."*

*"I had a meditation technique that I started when I was driving down [to cancer treatment] from home. My mom or dad would drive me, and then I use it throughout the treatment."*

Other coping strategies included attending a survivor's support group, exercise, yoga, and being highly compliant with self-care recommendations provided by the interdisciplinary health team.

*"I used to cycle back and forth to the clinic and, you know, it's such a beautiful spot. But that was sort of my, I felt my therapy was just getting out and exercising. So, none of the side effects really affected that. It makes such a difference."*

The strength of participants was equally matched by their altruism and desire to help future patients. Each interview concluded by asking participants whether they are interested in contributing to the next phase of this research. Each participant agreed, with several expressing a very high degree of interest and motivation to collaborate further.

*"I'm just encouraged and I'm so excited that people like you to do more than their job to make it better for other people later and that's my motivation to participate is that this was hard for me but if I can help someone else who's struggling or who's trying to do a better job, whether it's someone like you who works at the hospital or whether it's a person who has, the you know, the problem and needs to get help, or the family's like anything that can help. Like it was a really hard thing I really would like to, you know, do my part as a citizen."*

*"I appreciate the opportunity to share my feedback and I hope that it helps somebody else in the future. They don't have to have that happen."*

Some participants expressed participation as being cathartic:

*"I feel good that I've shared all this, even some of my bitter disappointments, as well but I hopefully it wasn't too personal but at the same time there- it's my real experience so it's important to hear those things."*

*"I'm really grateful. I'm finding this very positive and encouraging."*

## Discussion

Our findings on the patient experience through treatment for HNC are consistent with the literature on the patient experience and information needs.<sup>9-15</sup> While each instance shared by participants could be classified as being positive or negative, such classifications would be an oversimplification as emotions were frequently layered, with feelings such as "gratitude" often tied to both "positive" and "negative" experiences. Applications of the Ambulatory Oncology Patient Satisfaction Survey across Canada also highlight the nuanced nature of patient experiences with cancer systems, including information provision.<sup>12-15</sup>

As shown in our findings, participants expressed feeling overwhelmed by the volume and complexity of information. However, they also described moments of needing more information and feeling frustrated when resources provided by healthcare professionals were overly simplified and generalizable. This demonstrates the ebb and flow of information needs and importance of providing the right information at the right time, otherwise rendering the patient overwhelmed and under-prepared.

The primary finding from a series of in-depth interviews with patients who underwent concurrent chemoradiation therapy for HNC was that patients need comprehensive information about their treatment yet “some of the patients did not even comprehend what they should know or ask.”<sup>16</sup> Those who performed self-research prior to oncologist consults were able to form a list of questions and better engage in medical decision making, consistent with our participants who felt using a decision support tool prior to seeing their oncologist would prepare them for active engagement in medical decision making.

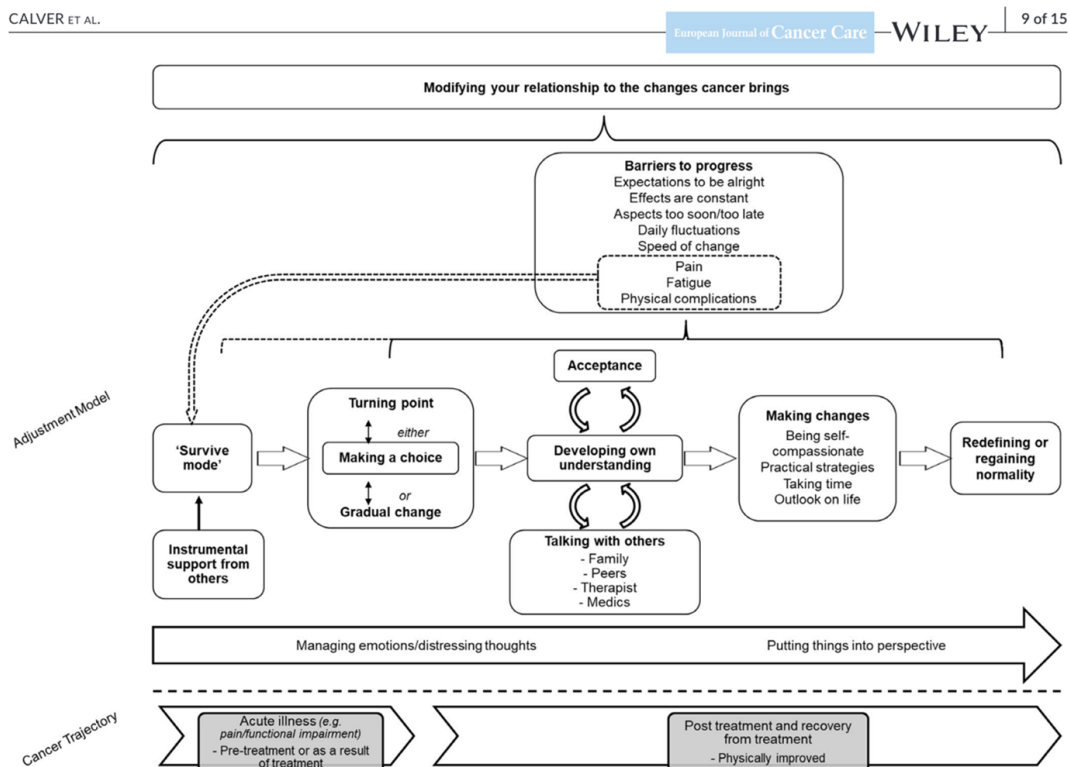
It is evident that patients want tailored information. Though general statistics and generic pamphlets have been found to be informative, it is not a replacement for tailored information.<sup>16,17</sup> Our participants described and exuded emotion when recounting frustrations over not getting their questions answered in a direct and robust manner. Though a content analysis of Instagram, the lived experiences with HNC survivorship was characterised and found, “acute and chronic fatigue and psychological stress are often not fully addressed by oncology providers.”<sup>18</sup>

Our participants wanted to feel cared for as an individual, not just a “number” pushed through the system. In a seminar by Professor Sir Ian Kennedy,<sup>19</sup> a renowned lawyer specializing in the health ethics, he “urged health

professionals to recognise that patients had become a form of currency through which capacity of services are measured, rather than a person who is understood and cared for.”<sup>24</sup> While we found unanimous appreciation for the caring nature of the healthcare professionals, several did express feeling like “just another case to fit into a formula” rather than being offered recommendations for best oncological outcomes and QOL. As a result, a third of our participants declined chemotherapy, despite the offer for dual modality treatment. This serves a call to healthcare professionals to re-examine how we conceptualize and integrate the patient experience into our practice.

Demonstrated in the results, patients found treatment and the healing phase to be an emotional experience. The psychological distress from diagnosis and treatment is well described.<sup>20-23</sup> What we need to grasp, however, is how to best support the psychological adjustment to these experiences. Calver et al.<sup>24</sup> propose a model of psychological adjustment to head and neck cancer can be mapped through the cancer trajectory, encapsulating the continuum of “managing emotions/distressing thoughts” to putting things in “perspective” (Figure 1). The authors emphasize that “the extent to which participants engage in each of the processes within the model may vary.”<sup>24</sup> The

Figure 1. A model of psychological adjustment to head and neck cancer by Calver et al<sup>24</sup>



results from the phenomenological approach taken in our study, rings true for this grounded theory model.

Limitations of this study include the non-probabilistic sampling method, exclusion of race and/or ethnicity from the demographics, and the lack of repeat interviews to improve data richness all of which limit the generalizability of results within this patient population. Furthermore, self-selection and recall biases may impact findings. Strengths, however, include the research teams' personal and phenomenological experiences with HNC through which to ground the study conceptualization, participant interactions, and data analysis. Additionally, attempts were made to diversify patient demographics and future plans are in place to ensure diverse racial representation.

## Conclusion

Understanding the patient experience can shape care delivery and ensure QOL is not overshadowed by survival outcomes. The patient experience must be considered through the full care trajectory and into survivorship to provide the right information to the correct patient at the optimal time. The danger of not recognizing the patient as the expert in the experience is "patients feel the experience of healthcare is routine, mundane and impersonal because they have become a currency through which they are being passed from one part of a system to another."<sup>24</sup> Patient journey mapping may be a novel approach to exploring the temporal relationship between information needs and the patient experience along the cancer continuum to uncover opportune moments, from the patient perspective, for knowledge and supportive care intervention. The model of psychological adjustment by Calver et al.,<sup>24</sup> can be considered to help inform the delivery of cancer care information in a method that recognizes the patient as the expert in their experiences.

This study contributes to the literature on information delivery as a proactive intervention to combatting psychological distress in patients with HNC. These findings will provide the phenomenological basis for the next phase of this work, co-creating an electronic decision-support tool with survivors of HNC, to facilitate shared decision making and enhance patient-centered care.

## Conflicts of Interest

Eleah Stringer received funding for this work from the BC Support Unit-Vancouver Island Centre. Dr. Andre Kushniruk receives research funding from Natural Sciences and Engineering Research Council of Canada (NSERC). Dr. Julian Lum receives research funding from the Canadian Institute for Health Research (CIHR). Dr. Jonathan Livergant has nothing to declare.

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## Appendix

### Supplement A: Interview script

Topic	Time allotment	Questions/ statements
Introduction	5 mins	Welcome, overview of study purpose, reminder of confidentiality and right to pass on any questions
Background	5 mins	Did you request copies of any of your medical records? Did you conduct self-research?
Experience	10 mins	What do you recall being told about treatment side effects and was your experience with side effects as you anticipated?
E-tools	10 mins	Overview of what they are, purpose What do you think about the use of visuals (pictures and videos) in helping explain treatment and its potential short- and long-term side effects? Do you think visual images such as pictures or videos would have had a different impact than the verbal explanation you received from your oncologist? Would a better understanding of side effects have influenced your feelings towards treatment? In retrospect, would you do anything differently?
Evaluation	15 mins	Present mock-up design What are your thoughts on this as a potential design? Anything lacking or excessive? How would you like it shown? (tablet, etc) User friendly? Can you imagine yourself using it when discussing treatment with your oncologist? What would you change?
Conclusion	5 mins	Any final thoughts or comments? Consent for follow-up interview? Thank you