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Category: Patient Experience and Supportive Care

Abstract

Introduction: Patients with head and neck cancer (HNC) may be offered a choice of treatments which can cause undue stress and anxiety when comprehending the options and making a decision congruent with personal values and health goals.
Methods: Informed by a scoping review on electronic decision aids (DAs) for patients with HNC and feedback from the interdisciplinary HNC care team, a prototype DA was created then presented to 12 survivors of HNC for feedback on its utility and design. The semi-structured interviews were thematically analyzed.
Results: 12 themes fell into three categories: (1)The patient experience- Patient have high, though varying information needs; an emotional experience; and stories of coping, strength and resiliency. (2)Electronic DAs and decision support- familiarity with DAs; support of concept: usefulness and of visual aids; and versatility of the prototype. (3)Evaluation of prototype- reaction to protype; favourited features; complexity; preference for customizability; suggestions for improvement; and presentation device.
Conclusion: All participants felt electronic DAs would support an accessible, thorough, and transparent explanation of treatment and side effects when used with an oncologist. Participants liked the simple design but desired more customizability to adapt to individual information needs. This highlights the value and utility of tools co-designed by survivors to engage patients, regardless of health literacy, in treatment decisions.

Background

Head and neck cancer (HNC) is the sixth leading type of cancer worldwide.[1] HNC is associated with substantial symptoms and functional losses such as impaired speech, eating, and breathing. Even after successful therapy, physical and psychosocial complaints persist resulting in long-term morbidity and reduced QOL.[2-4] The importance of quality of life (QOL) cannot be overemphasized because, in cancer generally, baseline QOL is one of the strongest available prognostic factors.[5,6]

Patients may be offered a variety of treatments which can be anxiety-inducing as its difficult to tease apart the pros and cons, despite having it explained by their oncologist, and can be particularly challenging in the context of cultural differences and limited health literacy.[7-9] Despite the change in etiology and patient characteristics over the last decade,[10,11] our methods of medical communication have not adapted.

Patient information needs on treatment options and side effects are not being met in our current model of information delivery, contributing to health inequities within cancer care. Multimedia interventions may offer a promising approach to addressing communication and information needs [8] as visual aids help modify incorrect expectations about treatment risk.[12]

Decision aids (DAs) "are interventions that support patients by making their decisions explicit, providing information about options and associated benefits/harms, and helping to clarify congruence between decisions and personal values".[13]

Learning Objectives

To qualitatively explore:
1. What do survivors of HNC think about the utility of an electronic decision-support tools utilizing visuals for patients with HN
2. What suggestions do survivors of HNC have on a potential design and features of a DA?

Methods

Example screens visualizations (ie. wireframes) for a prototype DA were developed, informed by a scoping review on DAs for patients with HNC[14], the researchers personal and professional experience with HNC, and input from the interdisciplinary care team. Users can hover their cursor along the curve (Figure 2a) to see a visual representation of the specified side effect (Figure 2b, 2c) to help demonstrate potential severity of treatment-related side effects over time. Symbols (circles and triangles) were used for demonstration purposes only, to exaggerate the hovering effect.

REB approval was received (UBC# H20-02307, UVic# BC20-0546). Participants were recruited through purposive and convenience sampling, aiming for 6-12 participants or until saturation reached. Inclusion criteria: diagnosis of HNC (including nasopharyngeal) of any staging, treatment completion within last 5 years at BCC, English proficiency.

Semi-structured interviews were conducted between May and July 2021 to answer the (above) research questions. Participants were shown the prototype design than asked for feedback. Interviews were over Zoom, audio-video recorded along with field notes and post-reflective questions, then transcribed. Data were analyzed using a six-step approach to reflexive thematic analysis[15].

Table 1. Participant demographics, n=12

Category	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	0 (0)
Treatment type	Surgery	5 (42)
	Radiation	12 (100)
	Chemotherapy	3 (25)
	Cisplatin	3 (25)
	Cetuximab	0 (0)
	Declined by participant	4 (33)
Involvement with symptom management team (GPO and RN)	Less than once per week	3 (25)
	Weekly	5 (42)
	Greater than once per week	4 (33)
Involvement with Patient and Family Counseling	None	2 (17)
	1-3 times through treatment	3 (25)
	>3 times through treatment	7 (58)

*Per medical chart; **Based on AJCC 8th edition (Amin et al., 2017)

Results

Twelve survivors of HNC were interviewed, see Table 1 for participant demographics. Sixty-one codes were applied pointing to 23 concepts which comprised 12 themes. Themes were further organized into three categories (Table 2). Samples of participant quotes supporting theme are shown in Figure 1.
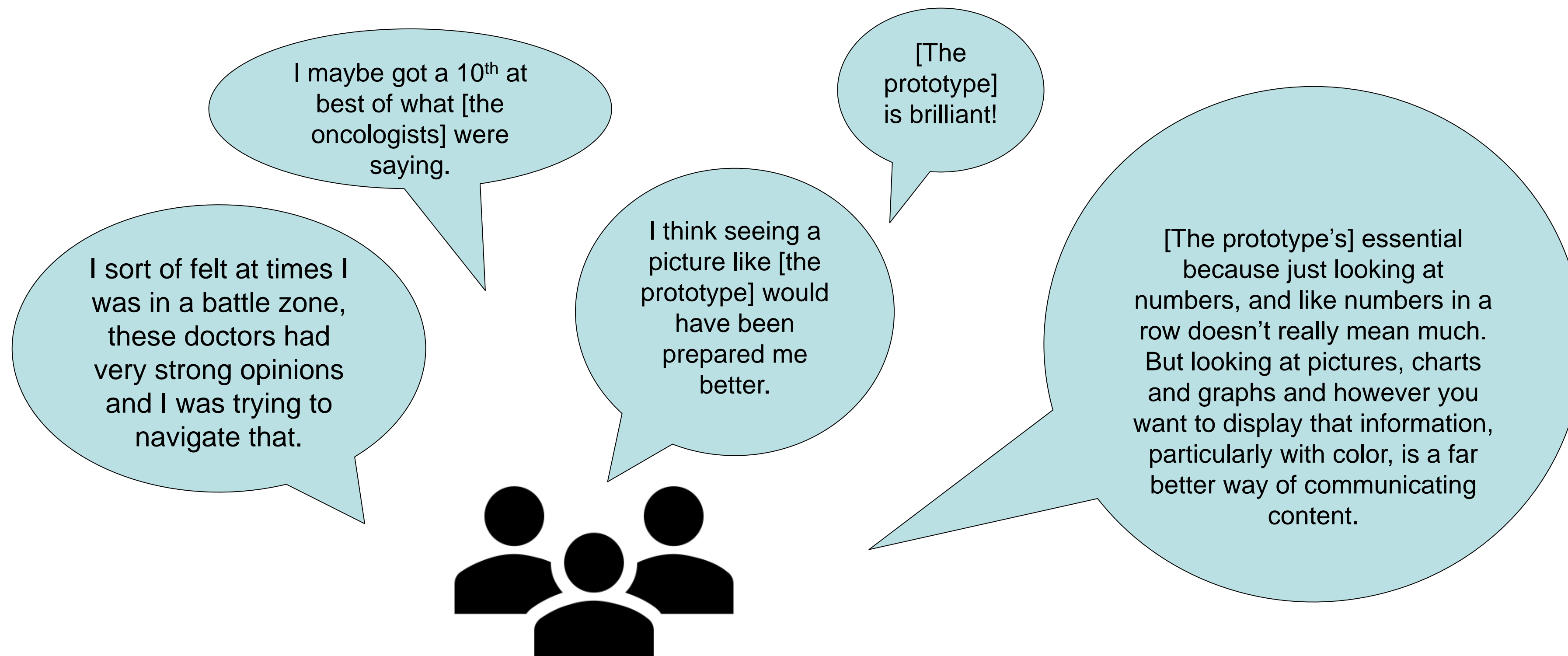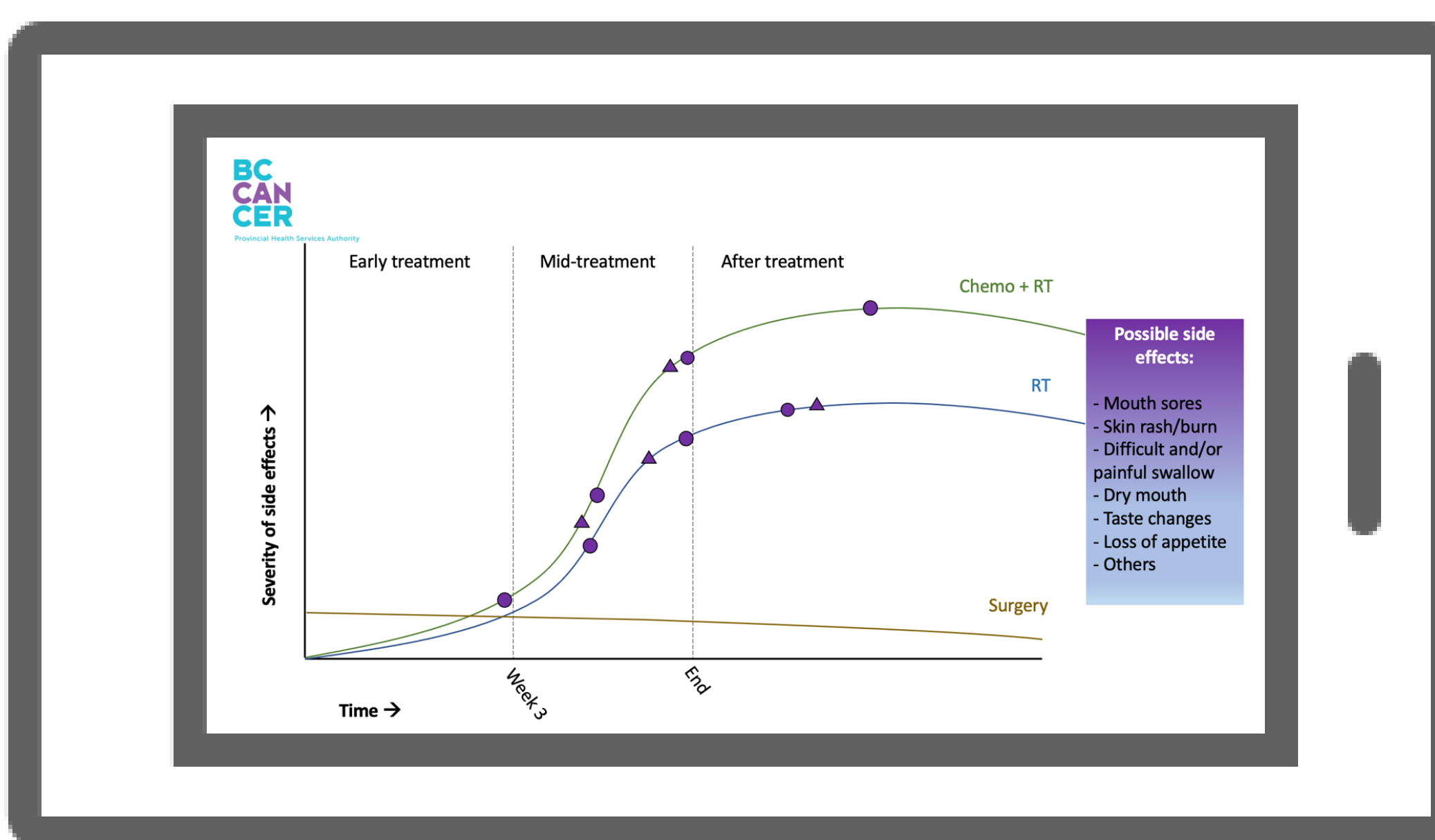

Figure 1. Samples participant quotes

Figure 2a. Wireframe of a home screen graph for a prototype DA (displayed to patients during interviews). Circles represent mucositis, triangles represent radiation dermatitis
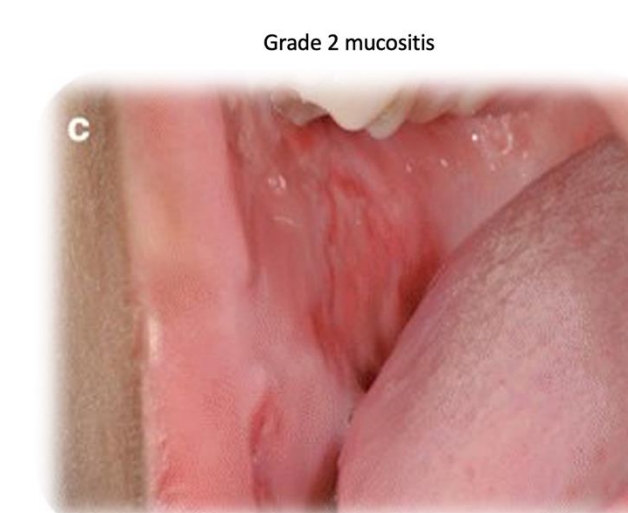

Figure 2b. Example image with CTCAE grading and name (mucositis)

Figure 2c. Example image with CTCAE grading and name (radiation dermatitis)

Table 2. Thematic categories and Concepts

Category	Themes	Concepts
Patient experience	(1) Patients have high, though varying, information needs; (2) An emotional experience; (3) Stories of coping, strength and resiliency;	(1) Information needs; (2) Fear of the unknown; (3) Desire for personalized information; (4) Varying degrees of information needs; (5) Fear as a motivator vs stressor; (6) High information needs on life after treatment;
E-tools and decision support	(4) Familiarity with DAs; (5) Support of concept: usefulness and value of visual aids in explaining treatment and its side effects; (6) Versatility of prototype;	(7) Support of concept; (8) Appreciation for learning with visuals; (9) Communication; (10) Patients would use the app in different ways; (11) Design and features; (12) Emotion, traumatic experience, and resiliency; (13) Emotional impact of physical changes that can be seen by others; (14) Trend for a specific symptom to leave a large, lasting impact; (15) Coping strategies; (16) Altruism; (17) Meditation/ mindfulness;
Evaluation of mock-up	(7) Reaction to prototype; (8) Favourited features; (9) Preference for customizability; (10) Complexity; (11) Suggestions for improvement; (12) Presentation type.	(18) Recommendations; (19) Appreciation for the care team; (20) Areas for improvement within the care team; (21) List of practical suggestions; (22) Differences in experiences pre and during COVID-19; (23) Value of family and connecting with other patients.

Discussion

1. Participant feedback was overwhelmingly supportive of using visuals to advance patient autonomy, consistent with literature demonstrating patients prefer images to illustrate benefit-harm trade-off in health contexts.[16]

2. Patients have unique needs so DAs must be customizable meet range of information needs, learning styles and preferences. Participants were interested in adding interactive options, particularly symptom tracking which is shown to improve health outcome and communication with healthcare providers.[17] Participants envisioned themselves using this not only as an educational platform, but also as a communication device, scheduler and tracker.

Limitations

Our prototype did not include information on prognosis or survival as it's designed to be used with an oncologist who can discuss prognosis on a case-by-case basis. Previous research, however, demonstrates that patients understand medical information on survival and cancer treatment options equally or better when shown with mortality statistics.[18] In a viewpoint paper of Dr. Kushniruk's based on his personal experience, he argues for "patients to be more informed about choices and statistics, including the meaning of survival curves in relation to different treatment options."[19] Selection bias was introduced through sampling methods. The prototype design did not adhere to a formal development process such as the IPDASC.[20]

Conclusion

This research centers the patient-voice, which overwhelmingly supports the use of visual and tech-based innovations to improve the accessibility of cancer treatment information to engage all patients, regardless of health literacy, in collaborative decision making. Additionally, this research highlights the value of used-centered design, rooted in acceptability and utility, in medical health informatics, recognizing cancer survivors as the ultimate knowledge-holders.

Next Steps

A decision aid, the Head and Neck Application for Patients and their Partners (HANC APP) is being co-designed with the interdisciplinary HNC tumor team, including oncologists, (Dr. Sally Smith and Dr. Jonathaan Livergant), HNC surgeon (Dr. Eitan Prisman), health informatics researchers (Dr. Elizabeth Boryicki and Dr. Andre Kushniruk) and survivors of HNC then tested in the clinic at BC Cancer- Victoria. Learn more about the HANC APP Study, under co-PIs Dr. Sally Smith and Dr. Jonathan Livergant, at www.bccrc.ca/dept/nahr/projects. or Contact the Study Lead and Investigator, Eleah Stringer eleah.stringer@bccancer.bc.ca

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