"Engage the person": Utility of electronic decision aids for patients with head and neck cancer, a scoping review

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Abstract

Introduction: Patients with head and neck cancer (HNC) carry a significant symptom burden, function alterations, and decreased quality of life. Furthermore, treatment impacts social activities and interactions as patients report reduced sexuality and high rates of depression. Patients may suffer undue anxiety because they find treatment incomprehensible, which is partially a function of limited, understandable information. Patients' perceptions of obtaining adequate information prior and during treatment are predictive of positive outcomes. Compared to usual care, decision aids (DAs) may increase patients' knowledge, accuracy of risk perception, and congruency between values and care choices allowing them to partake in active decision-making.

Methods: A scoping review evaluated the range and nature of electronic DAs researched and/or trialed for patients with HNC. Six databases, reference lists and grey literature were searched from January 2010 to 2021. Articles on electronic DAs for oncology patients were searched then further sorted by specificity for HNC.

Results: The search returned 4217 articles for oncology but only 167 for HNC. Twelve articles met inclusion criteria and were incorporated in the analysis. Five DAs have been created with varying design characteristics but four consistent themes: (1) patients and physicians valued DAs; (2) usefulness of visuals; (3) DA use lessened decisional conflict and anxiety and improved knowledge, satisfaction and shared decision-making; (4) varying levels of patient information needs.

Conclusion: Findings demonstrate the paucity of electronic, DAs for patients with HNC and confirms that patient-centered decision-support, with visual images, may improve understanding of treatment options and risks to improve satisfaction with their decision and consultation, while reducing decisional conflict.

Background

Head and neck cancer (HNC) is associated with substantial symptom burden.[1-3]. Patients in Western Canada with HPV-associated HNC are demonstrated to have high information needs.[4] Some patients with HNC struggle to take part in decision-making regarding treatment options because of the complexity of information that needs to be accurately conveyed [1,5], which can be particularly challenging for patients with limited health literacy.[1] Providing balanced and comprehensive information is imperative from an ethical and safety perspective.[6]

Decision aids (DAs) **"are interventions that support patients by making their decisions explicit, providing information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values."**[7] They complement, rather than replace, counselling from a healthcare practitioner as an interactional strategy to facilitate patient involvement in discussions and decisions about healthcare and thereby contribute to patient concordance.[5] DAs can be useful when the best strategy for an individual depends on their preference for the benefit/harm trade-off inherent in a particular choice and help reduce decisional conflict.[8]

Multimedia interventions may offer a promising approach to addressing risk communication and information needs[1] as visual aids help to modify incorrect expectations about treatment risk.[9,10] Findings derived from cancer populations suggest that electronic programs may not only be an effective and cost-efficient approach for delivering information and improving safety, but may also represent an acceptable and feasible format for communicating information about multiple topics that can be tailored to meet the unique needs of patients and family members.[1]

Learning Objectives

Research questions:
1) What decision aids (DAs) have been researched and/or trialed for patients with head and neck cancer (HNC)?
2) What are the successes and criticisms of these tools?
3) What recommendations does this literature provide for future studies?

Methods

A scoping review was conducted follow the six-stage framework of Arksey and O'Malley[11] while engaging in each stage with an iterative and reflexive approach : (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) collecting data and data items; (5) and reporting on results. The optional, sixth step of data validation through consultation was not conducted.

Table 1. PRISMA diagram of article selection

Inclusion	Exclusion
- Discussed electronic decision-support tools for patients with HNC or other cancers - Available online	- Discussed tools intended for physician/oncologist use - Discussed tools that were not electronic - Were published in non-English language - Were only available in hard copy - Were not peer-reviewed, published studies - Focused on surgery only - Intended for the pediatrics

A systematic search strategy was developed around selected inclusion and exclusion criteria (Table 1) then optimized by a librarian at the University of Victoria. Research databases searched included CENTRAL®, CINAHL®, Embase®, Ovid MEDLINE®, PubMed®, and IEEE Xplore® and were limited to publications in English within the past 10 years (January 2010-2021). Search terms were expanded with Boolean truncation (ex. asterisk wildcard symbol to capture variations of the search terms) and operators "AND" was used to combine mandatory key terms and "OR" used to group similar terms. Medical Subject Headings (MeSH) were searched, and expanders applied with applicable databases. Various combinations of terms were run until no new results were found. References from relevant articles were searched for additional publications. Grey-literature was hand-searched through Google and Google Scholar.

All results were compiled in Zotero® software (Version 5.0.93, 2020) and duplicates merged. Results specific to HNC were manually sorted then selection criteria applied as defined in Table 1. Final article selection was performed in a three-stage process by researchers.

The articles selected for full review (full citations in Table 3) were sifted and charted using a "descriptive-analytical" method of narrative charting was completed with a "data extraction form."[12] The features of the DA, target population, and recommendations were summarized for each article. Articles were collated and thematically analysed for themes. Unlike a systematic review, however, evidence was not synthesized nor were aggregate findings presented.[12]

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Results

Developed Decision Aids (DAs)

The final results yielded 11 academic sources and one grey literature source (see Figure 1), representing five different tools, as two DAs produced multiple publications. Each tool was specific to a particular tumor location and/or staging, with 84% of the articles from Canada. The DAs can be classified into one of two categories: designed to be used as adjunct material during a physician consult or independently, outside of clinical encounters. Those designed to be used independently as adjunct material had augmented comprehensibility. There was varying degrees of detail provided on the how the tools were created and tested (Table 2).
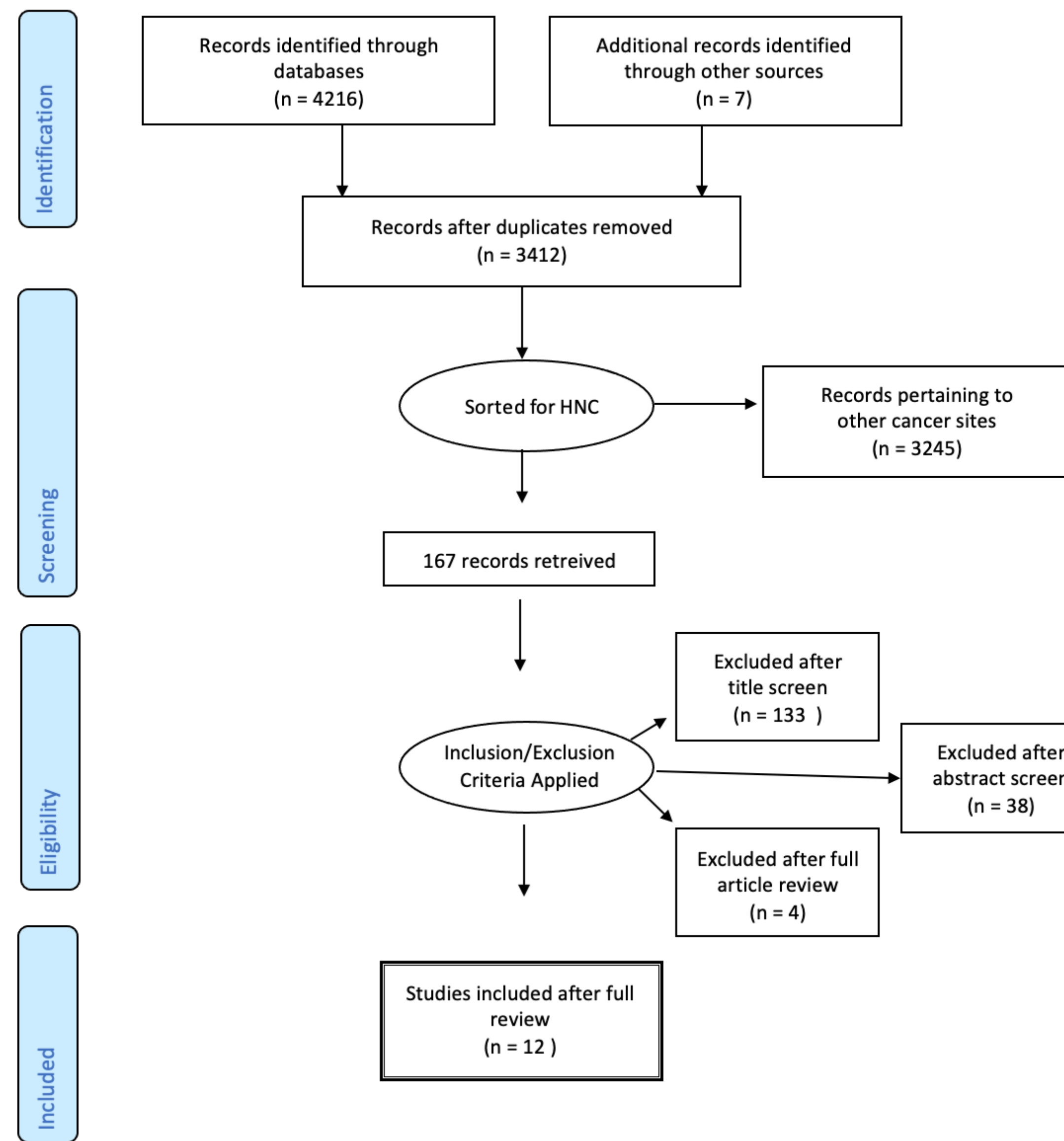

Figure 1. PRISMA diagram of article selection

Themes

Despite the heterogeneity of design characteristics, there were four consistent themes. The first is that both patients and physicians valued DAs as "the tool was felt to positively supplement, but not… replace, the clinical-patient encounter."[13] This theme was further supported in the qualitative results from Sawka et al.[14] which found physician counselling to still be important in affecting the ultimate treatment decision while providing human contact that was necessary to meet the supportive, psychosocial needs of the patient.

The second strong theme is that DA should be visually supported by images. Interviews with physicians found "the relatively low average educational level of the typical patient" to be a barrier to good patient counseling. As a result, they recommended that "the optimal PDA should be visually supported by images and be easy to navigate through."[15]

Third, use of a DA lessened decisional conflict and anxiety and improved knowledge, satisfaction, and shared decision-making. These results were mirrored by Sawka et al.[16] where decisional conflict was reduced in all respective subscales of the tools compared to the control group.

Though the above themes demonstrate the use of electronic DAs to be valuable and effective, several of studies observed patient preferences for a varying degree of information.

Table 2. Summary of DAs

Publication*	Tumor site & staging	Country	Intended Use	Created by	Testing
Petersen et al. 2019	Advanced larynx Ca	Netherlands	Independent	Needs assessment; comprehensibility & usability; minor tweaks made then beta-tested	
Lam et al. 2017	Early-stage oropharyngeal SCC	Canada	Physician	Not specified	Piloted in a single institution, 40 healthy individuals; trade-off point was investigated
D'Souza et al. 2013 a, b; 2017	Stage III and IV HNC	Canada	Independently	HNC team	Non-RCT, 103 pts; duplicated in partners
Sawka et al. 2011 a, b, c; 2012; 2015 a, b	Post-thyroidectomy, early-stage papillary thyroid Ca	Canada	Physician	Multidisciplinary team, guided by survivors & physician experts	1) Usability testing 2) Piloted in 50 pts 3)Trialed in single-centre, parallel design, RCT at Toronto General Hospital
Cardiff, n.d.	Early Ca of the tonsil, early Ca of the vocal cords, Ca of the larynx	UK	Physician	HNC team	Not specified

Future Recommendations

Nearly all authors recommended further testing of existing DAs. Other future recommendations posed in study conclusions include: (1) assessing whether DAs for other cancer treatment choices subject to similar uncertainty in the medical evidence can improve the decision-making process, long-term health and psycho-social outcomes[16]; (2) further understanding how individual information preferences may impact medical knowledge acquisition and decision-making[16]; (3) exploring whether format personalization and customizing the level of detail of content (particularly relating to numerical data) of DAs to users' preferences may optimize knowledge translation outcomes[16]; (4) understanding the evolving role of personalization of decision support tools in advancing patient autonomy regarding provision of information[14]; (5) investigating the longer-term effects of PDA[14]; (6) considering the cost-benefit analysis[17]; (7) exploring the extent or severity of patients' informational needs[17]; (8) exploring potential barriers to their healthcare teams in delivering this information to patients[17]; (9) testing the feasibility and satisfaction among newly diagnosed patients as well as physicians and other healthcare providers.[13]

Conclusions

This scoping review demonstrates the paucity of literature on electronic decision-support tools for patients with HNC, especially in comparison to other tumor sites. Four themes were woven through these articles and are consistent with the research in their respective fields. **This scoping review demonstrates that DAs in this population have been viewed as a positive addition to standard clinical encounters and supports future work in this area. Furthermore, it demonstrates the value of involving survivors HNC in the development and implementation of DAs for patients with HNC to address health literacy and shared decision-making with the ultimate goal of reducing decisional conflict and improving QOL.** The long-term impact of DAs, including impact on outcomes, patient understanding and reduction of error warrants further investigation.

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. Jonathathan 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

Acknowledgements & Declarations of Conflict

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Table 3. Full references of included articles

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