Shared Decision Making in Oropharyngeal Cancer: The Development of a Decision Aid for Resectable Oropharyngeal Carcinoma, a Mixed Methods Study

Authors: Anne N. Heirman, Lisette van der Molen, Richard Dirven, Gyorgi B. Halmos, Michiel W.M. van den Brekel Abstract: Background: Due to the rising incidence of oropharyngeal squamous cell cancer (OPSCC), many patients are challenged with choosing between transoral(robotic) surgery and radiotherapy, with equal survival and oncological outcomes. Also, functional outcomes are of little difference over the years. With this study, the wants and needs of patients and caregivers are identified to develop a comprehensible patient decision aid (PDA). Methods: The development of this PDA is based on the International Patient Decision Aid Standards criteria. In phase 1, relevant literature was reviewed and compared to current counseling papers. We interviewed ten post-treatment patients and ten doctors from four head and neck centers in the Netherlands, which were transcribed verbatim and analyzed. With these results, the first draft of the PDA was developed. Phase 2 beholds testing the first draft for comprehensibility and usability. Phase 3 beholds testing for feasibility. After this phase, the final version of the PDA was developed. Results: All doctors and patients agreed a PDA was needed. Phase 1 showed that 50% of patients felt well-informed after standard care and 35% missed information about treatment possibilities. Side effects and functional outcomes were rated as the most important for decision-making. With this information, the first version was developed. Doctors and patients stated (phase 2) that they were satisfied with the comprehensibility and usability, but there was too much text. The PDA underwent text reduction revisions and got more graphics. After revisions, all doctors found the PDA feasible and would contribute to regular counseling. Patients were satisfied with the results and wished they would have seen it before their treatment. Conclusion: Decision-making for OPSCC should focus on differences in side-effects and functional outcomes. Patients and doctors found the PDA to be of great value. Future research will explore the benefits of the PDA in clinical practice.

Keywords: head-and-neck oncology, oropharyngeal cancer, patient decision aid, development, shared decision making

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