Patient-Reported Information Gaps Regarding HPV-Mediated Oropharyngeal Cancer in a Rural State

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BACKGROUND

- Each year in the US, there is an estimate of over 16,000 new cases of human papillomavirus-mediated oropharyngeal cancers (HPV+OPSCC), and the incidence of this disease is rising.[1]
- Contrary to alcohol and tobacco use as etiologic agents for HPV-negative head and neck cancers, the general public remain largely unaware of its role in OPSCC.[2]
- In Kentucky, 57% of adolescents between the ages of 13 and 17 have received the HPV vaccine, reflecting one of the lowest vaccination rates in the country.[3]
- Work toward the beginning of the understanding of HPV as a distinct etiologic agent showed high anxiety and significant knowledge gaps regarding both HPV and cancer treatment at diagnosis of HPV-OPC.

RESEARCH QUESTIONS

- What are the current knowledge gaps for patients with HPV+OPSCC in the state of Kentucky?
- What are the factors influencing patient experience and anxiety living with HPV+OPSCC?

METHODS

- Participants diagnosed with HPV+OPSCC between 6/2021 – 12/2023 and treated at the NCI-Designated Markey Cancer Center in Lexington, KY were contacted by telephone
- Participants were asked to recall what questions they had at the time of diagnosis
- Participants were also asked to complete a telephone-based survey model based on a metropolitan study a decade prior.[4]

192 HPV+OPSCC participants were attempted to be contacted by telephone → 75 HPV+OPSCC participants were successfully contacted and the study was introduced → 43 HPV+OPSCC participants completed the interview

- Demographically, the median age was 65 (Range=32), 84% male, with 98% of participants identifying as white
- Of the 44 participants who completed the telephone interview, 32 participants agreed to provide further demographic information: 24 were married, and 14 had obtained a college degree or higher

RESULTS

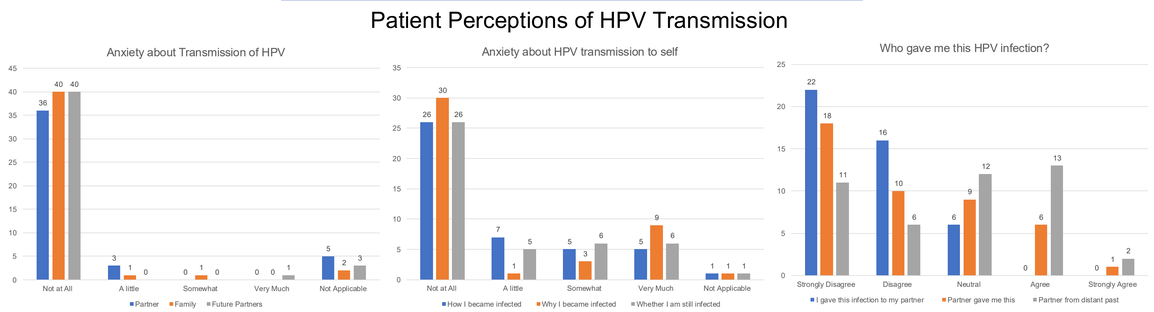

Figure 1: Most participants report no anxiety at all about transmission of HPV, but do not have a strong inclination of where their HPV came from

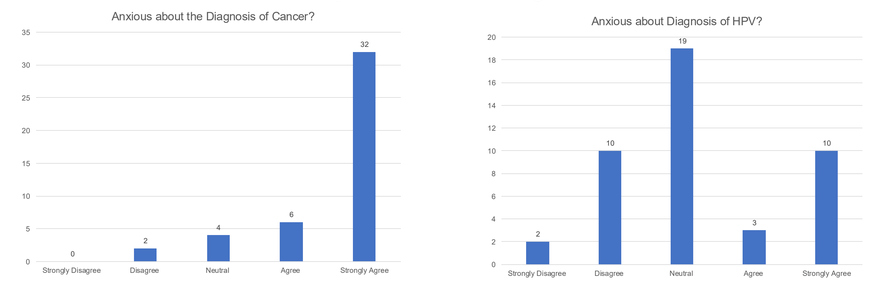

Figure 2: 73% of participants strongly agreed that they were anxious about the diagnosis of cancer, yet only 23% strongly agreed that they were anxious about the diagnosis of HPV

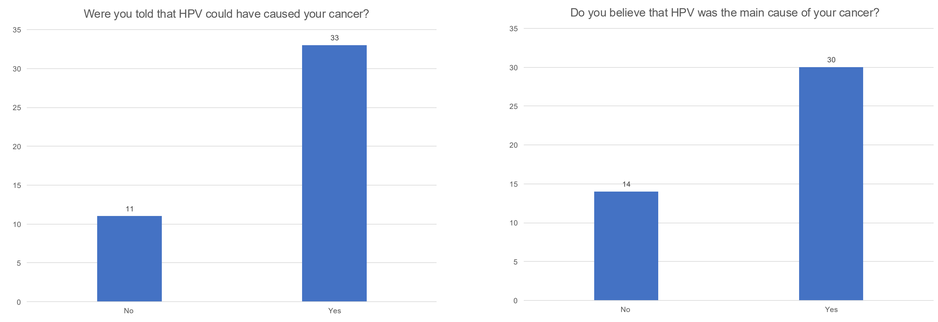

Figure 3: 75% of participants recalled being told about HPV as a causative agent of their cancer and 68% believed it was the main cause

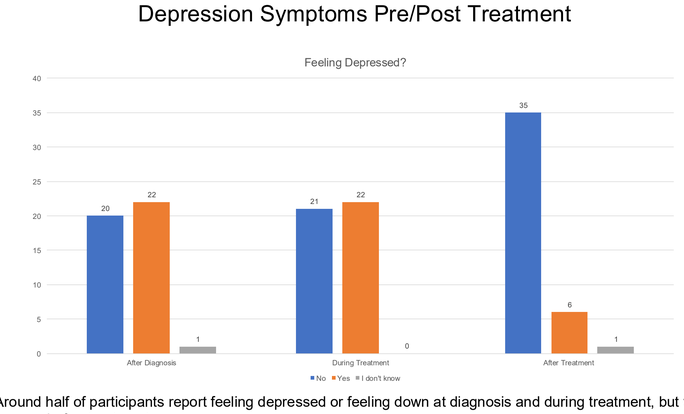

Figure 4: Around half of participants report feeling depressed or feeling down at diagnosis and during treatment, but very few (14%) still feel depressed after treatment

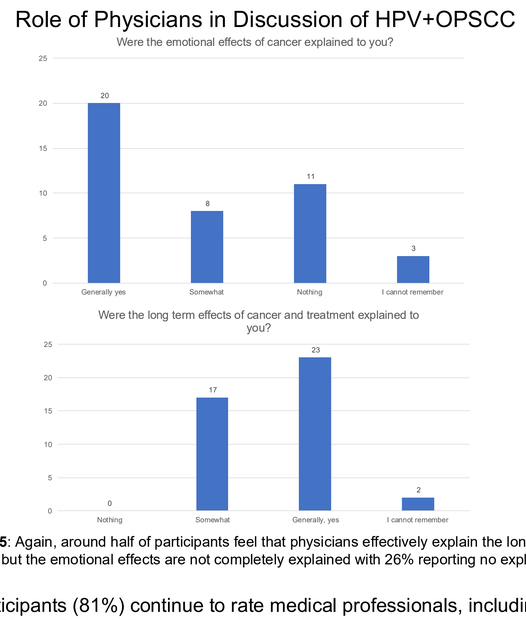

Figure 5: Again, around half of participants feel that physicians effectively explain the long-term effects, but the emotional effects are not completely explained with 26% reporting no explanation

- Participants (81%) continue to rate medical professionals, including board-certified medical oncologists, radiation oncologists, head and neck surgeons as “very helpful” for information about HPV
- Nurses (65%) and printed information from the clinic (58%) are rated as ”very helpful” for information
- Only 40% of participants rated the internet as very helpful.
- Participants were asked what questions they wish they asked their doctors about their HPV+OPSCC and what kind of questions they searched on the internet
- The most common thread of questions found in the interviews included: “What is HPV”, ”What caused it”, ”treatment side effects” and “cure rates of HPV+OPSCC”

CONCLUSIONS

- Knowledge gaps regarding HPV+OPSCC **persist** among present-day survivors.
- Compared with prior work performed in a metropolitan population a decade ago, patients were more anxious about cancer and relatively less anxious about HPV diagnosis and transmission. Participants continue to heavily rate providers, but **less positively rate the internet for answers to questions.**
- Participants feel that discussion of the long-term effects of cancer are explained well, through **discussion of the emotional effects of cancer could be improved.**
- This study supports future work aimed at generating patient-support educational materials and survivorship interventions.

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