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# The complicated ‘Yes’: Decision-making processes and receptivity to lung cancer screening among head and neck cancer survivors

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### ABSTRACT

**Objective:** Shared decision making (SDM) is recommended when offering lung cancer screening (LCS)—which presents challenges with tobacco-related cancer survivors because they were excluded from clinical trials. Our objective was to characterize head and neck cancer (HNC) survivors’ knowledge, attitudes, and beliefs toward LCS and SDM.

**Methods:** Between November 2017 and June 2018, we conducted semi-structured qualitative interviews with 19 HNC survivors, focusing on patients’ cancer and smoking history, receptivity to and perceptions of LCS, and decision-making preferences

**Results:** Participants were receptive to LCS, referencing their successful HNC outcomes. They perceived that LCS might reduce uncertainty and emphasized the potential benefits of early diagnosis. Some expressed concern over costs or overdiagnosis, but most minimized potential harms, including false positives and radiation exposure. Participants preferred in-person LCS discussions, often ideally with their cancer specialist.

**Conclusion and Practice Implications:** HNC survivors may have overly optimistic expectations for LCS, and clinicians need to account for this in SDM discussions. Supporting these patients in making informed decisions will be challenging because we lack clinical data on the potential benefits and harms of LCS for cancer survivors. While some patients prefer discussing LCS with their cancer specialists, the ability of specialists to support high-quality decision making is uncertain.

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## 1. Introduction

Lung cancer is the leading cause of cancer-related deaths in the United States [1]. While 5-year survival is 65% for early-stage lung cancers, most lung cancers are diagnosed at advanced stage when survival is 16% [2]. The National Lung Screening Trial (NLST) found that lung cancer screening (LCS) with low-dose CT scans (LDCT) reduced lung cancer mortality by 20% compared to screening with chest radiographs [3]. Based in large part on the NLST results, in 2013 the US Preventive Services Task Force (USPSTF) issued a Grade

B recommendation supporting LDCT screening of high-risk patients, including adults ages 55 to 80 years, with at least a 30-pack-year smoking history, who currently smoke or have quit within 15 years [4].

The National Comprehensive Cancer Network (NCCN) broadened eligibility criteria to include additional risk factors, including a history of head and neck cancer (HNC) [5]. The NCCN recommended considering screening these survivors beginning at age 50 if they had at least a 20-pack-year smoking history. Additionally, the Centers for Medicare & Medicaid Services (CMS) issued a national coverage determination for reimbursement, requiring clinicians to engage patients in shared decision making using a decision aid [6]. Survivorship guidelines from the American Cancer Society recommended that LCS discussions take place in the primary care setting [7].

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However, there are multiple challenges to considering LCS discussions for HNC survivors. Little evidence exists that primary care providers can effectively hold LCS discussions with eligible patients without a cancer history [8], let alone among cancer survivors. Data suggest that primary care providers have limited awareness of lung cancer screening clinical trial results or professional society guidelines [9–14]. In the past, studies have shown that primary care providers often fail to present balanced information regarding cancer-screening decisions for breast, colorectal, and prostate cancer. While decision aids can greatly facilitate these discussions, the available decision aids present NLST data, which may not be applicable to HNC survivors because cancer survivors were not eligible for the study [15]. Epidemiologic data suggest that early stage lung cancer has a greater mortality impact on HNC survivors than individuals with no prior cancer history, which might limit the mortality benefit of lung cancer screening for HNC survivors [16].

These issues call into question both how to conceptualize the overall benefits and risks of LCS for HNC survivors, and how and where to discuss LCS. Despite increased research into patient perceptions of LCS [10,17–21], little is known about cancer survivors' perceptions. We conducted a qualitative study to examine the knowledge, attitudes, and decision-making preferences about LCS among HNC survivors.

## 2. Methods

### 2.1. Subjects and settings

We recruited participants through the Otolaryngology Clinic at The University of Iowa Hospitals and Clinics (UIHC), an academic tertiary facility. Eligibility criteria included 1) diagnosis of HNC, including oral cavity, oropharyngeal, or laryngeal cancers, 2) being free of any known persistent or recurrent upper aerodigestive tract cancer at least one year after completion of cancer-directed therapy, and 3) having at least a 20-pack-year smoking history. Once identified as eligible by treating clinicians through chart review, patients were approached during routine clinic appointments by the PI (NP) or research assistant (NK). Patients agreeing to participate were consented by the research assistant, using written informed consent, and interviewed by qualitative team members (KD, AS).

Between November 2016 and June 2017, we conducted interviews with 19 participants, of whom four were women and all identified as white, non-Hispanic. Most participants ( $n = 18$ ) met the NCCN's age eligibility criteria (50 to 74-years-old), and all reporting having completed their treatment at least one year prior to interview (years since treatment ranged from 1 to 21). We stopped recruitment once we reached consensus that we had achieved thematic saturation with our population of head and neck cancer survivors. The study was approved by the University of Iowa Institutional Review Board.

### 2.2. Data collection

We conducted one-on-one, in-depth interviews to elicit participants' unique experiences and perspectives. A semi-structured format allowed interviewers to focus on key domains while inviting participants to express what they felt was critical. The interview guide focused on five domains: 1) cancer history, 2) smoking and cessation history, 3) beliefs about and receptivity to screening, 4) perceived risks, benefits, and challenges of LCS, and 5) preferences about LCS decision making. Immediately after interviews concluded, we administered a questionnaire to obtain demographic data and smoking history. The interview process

lasted between one and two hours, and all participants received a \$75 gift card and a parking voucher.

### 2.3. Data analysis

Through a content-driven, iterative analysis, we explored patients' understanding of LCS and their receptivity to screening given their previous experience with cancer. Interview transcripts were imported into MAXQDA 11™ (VERBI GmbH), a qualitative data management software program. Qualitative team members (KD, AS, MVB) first reviewed a subset of transcripts to develop a codebook using *a priori* deductive codes, generated by the project's specific aims and research questions, and inductive codes that emerged during analysis. Team members iteratively adapted the codebook as analysis progressed. All qualitative team members reviewed interview transcripts independently and then jointly coded for consensus on themes, or analytic categories. Differences were resolved by team consensus. Emergent findings were presented regularly to the study team, who also helped review individual transcripts, modify the codebook, and interpret findings. The primary results discussed in this article and representative quotations are presented in Table 1.

## 3. Results

### 3.1. Participant characteristics

All 19 participants had been treated for HNC with surgical resection, radiation, and/or chemotherapy. Three patients were current smokers, and 16 reported having quit. Of the former smokers, three had quit longer than 15 years before, and six reported quitting as a result of their diagnosis. Table 2 presents sociodemographic information and smoking histories.

### 3.2. Knowledge of screening and LCS

Many participants reported currently engaging in some screening, notably for prostate, colorectal, and/or breast cancer. However, most participants reported being unaware of LDCT screening. The few who were aware had received the information from their HNC specialist.

Overall, participants lacked a general understanding of screening's purpose as distinguished from other testing. When asked about screening tests, many offered examples of diagnostic testing recommended due to symptoms. Specifically discussing LCS, participants talked in terms of finding a cancer, rather than negative or suspicious findings despite the substantially higher prevalence of the latter. Most participants did not discuss distinguishing between surveillance monitoring for HNC metastases to the lungs and screening tests for a second primary lung cancer.

### 3.3. Receptivity to LCS and decision-making considerations for HNC survivors

Participants were overwhelmingly receptive to screening and specifically to LCS with LDCT. They had few concerns about LCS and the possible harms of screening, focusing on the potential for early detection and treatment. One person, when asked whether anything would dissuade him from screening, said: "[N]ot unless it involved acid and branding irons or something like that. No. . . . I wouldn't hesitate to do it" (P7). Even participants expressing ambivalence said they would screen if their provider recommended it. Most recognized their increased lung cancer risk and felt LCS was appropriate for them. Participants' receptivity to LCS

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