

# Thyroid cancer patients opting for non-intervention report lack of support

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Dartmouth Institute Associate Professor Louise Davies recently led a study which examined the experiences of patients who opted not to intervene after receiving a diagnosis of thyroid cancer, despite the practice not being widely accepted. Credit: The Dartmouth Institute

Patients who choose not to intervene after a diagnosis of thyroid cancer face a challenging path—one that is often defined by a sense of isolation and anxiety, according to a first-of-its-kind study by researchers from The Dartmouth Institute for Health Policy and Clinical Practice and the Veteran's Administration in White River Junction, Vermont.

As the concept of cancer overdiagnosis—the identification of cancers that are unlikely to progress or cause the patient any harm—becomes

better understood by the public, a small but growing minority of patients diagnosed with thyroid cancer are deciding not to intervene. The researchers note that the overdiagnosis of thyroid cancer has particularly large health ramifications because by age 50, half of the population has at least one thyroid nodule, and by age 90, almost everyone does—making the portion of the population with potential for thyroid cancer diagnosis (or overdiagnosis) very large.

In the study, recently published in *JAMA Otolaryngology*, the researchers interviewed 22 people between the ages of 21-75 (average age of 49) who had decided not to intervene, despite this practice not being widely accepted. Study participants' thyroid cancer findings were all identified incidental to other health care activities, such as CT scans of the neck or chest, or evaluations of generalized symptoms such as weight gain. None of the study participants were experiencing any symptoms as a result of the thyroid cancer finding.

### **Among the study's key findings:**

- All 22 study participants questioned the course of treatment recommended by their physicians, but ultimate outcomes varied: 1 person had their cancer diagnosis reversed on obtaining a second opinion; 3 people ultimately decided to intervene. Reasons for non-intervention varied, with some participants quoting medical literature and published risk probabilities.
- Participants reported that their decision not to intervene received little support or reassurance from [health care](#) providers and others, and 12 (of the 18) participants reported receiving skeptical, even derisive responses, such as being told they were "stupid," "wrong," or "crazy."
- A large majority (15) of participants said they kept their thyroid cancer findings secret in order to avoid or manage this type of negative feedback, because as one person said, "untreated cancer

is a scarlet letter."

- Fourteen participants expressed a desire to hear about others' experiences of nonintervention or to connect with others going through a similar experience, yet only 3 individuals reported finding satisfactory support.
- As a result of participants overall experiences, 5 of the 18 had discontinued surveillance, the recommended alternative to intervention.
- Despite the challenges of choosing and living with non-intervention, 6 participants reported feeling glad they knew about their thyroid cancer finding; 4 were ambivalent, only 7 wished they did not know.

The researchers note that while their study focuses on individuals "who face the challenge of living with their cancers, overdiagnosis is also a challenge for doctors who must live with the uncertainty of potentially missing a case they might have been able to manage earlier."

"Culturally we are conditioned to think that if you're diagnosed with cancer, you have to do everything you can to rid your body of that cancer. Changing attitudes toward non-intervention is likely to require a change in our larger social and media culture," said senior author Louise Davies, MD, MS, associate professor at The Dartmouth Institute and Chief of Otolaryngology at Veterans Administration in White River Junction, Vermont.

In the meantime, Davies and her co-authors note that early adopters of non-intervention for [thyroid cancer](#) would likely benefit from increased social and health system support, including educational programs. Studies in other cancers such as prostate cancer, which have been known to have incidence of overdiagnosis, have shown that those who receive such support are more likely to continue monitoring their cancers.

**More information:** Louise Davies et al, Experience of US Patients Who Self-identify as Having an Overdiagnosed Thyroid Cancer, *JAMA Otolaryngology–Head & Neck Surgery* (2017). [DOI: 10.1001/jamaoto.2016.4749](https://doi.org/10.1001/jamaoto.2016.4749)

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