

# Study finds delayed side effects of head and neck cancer treatments go unreported

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New data from an Internet-based study show that patients with head and neck cancers (HNC) may be at risk for significant late effects after their treatment, but they're unlikely to discuss these and other survivorship care issues with their doctors. The findings, from researchers at the Perelman School of Medicine at the University of Pennsylvania, will be presented Monday, June 4, at the 2012 American Society of Clinical Oncology (ASCO) meeting in Chicago. The research team says the study reinforces the need to improve survivorship care for patients as they complete their active treatment, better educate patients about late effects they may experience, and encourage them to report these problems to their healthcare providers so they can be addressed.

Data from nearly 4,000 cancer survivors were gathered between April 2010 and October 2011 via patients who completed LIVESTRONG Care Plans via OncoLink, Penn Medicine's online cancer resource. Approximately four percent of those patients had been treated for a primary head or [neck cancer](#). Of those, nearly 88 percent reported having undergone radiation, 73 percent surgery, and 67 percent [chemotherapy](#). Many patients reported late effects such as difficulty swallowing/speaking (83 percent), decreased saliva production (88 percent), [thyroid](#) problems (33 percent), decreased neck mobility (60 percent), concerns regarding cognitive function (53 percent), or vision deficits. However, since results show that patients only discuss the survivorship care plans they created on the site with their [healthcare providers](#) in 55 percent of cases, the researchers are concerned that many of these symptoms are not being reported or treated. The most

common reasons for patients not sharing their survivorship care plans with healthcare providers were, "I did not think they would care," and "I did not want to upset or [anger](#) them."

"The fact that only about half of patients who create care plans are discussing them with [physicians](#) indicates a need for further development of patient counseling and survivorship care so we can deliver higher quality care to cancer survivors of all kinds," says lead author Christine E. Hill-Kayser, MD, an assistant professor of [Radiation Oncology](#) in the Perelman School of Medicine. "Our study indicates that as many as 45 percent of these late effects are going unreported, so it's possible that HNC patients may be at a higher risk for post-treatment side effects than we thought. But without understanding the true incidence of these problems, we can't properly screen for these problems or intervene to help patients when they develop them."

Patient-reported data were gathered from HNC survivors voluntarily using the LIVESTRONG Care Plan, a free Internet-based tool used to create survivorship care plans. The tool, available at [www.livestrongcareplan.com](http://www.livestrongcareplan.com) and through the OncoLink website, allows survivors to enter data regarding diagnosis, demographics, and treatments, and provides customized guidelines for future care and screening. Using this tool, HNC survivors were asked about any late effects they experienced following specific treatments. The authors say data reported in the new study may help shape future studies examining outcomes after HNC treatments, as well as patient counseling and survivor care plans.

Penn's Living Well After Cancer (LWAC) Program, for adult and childhood [cancer survivors](#), is a LIVESTRONG Survivorship Center of Excellence. This designation, awarded by the Lance Armstrong Foundation, reflects excellence in clinical care, research and education. Within the LWAC Program, the same nurse practitioners who care for

patients during their diagnosis and treatment help them develop an individualized survivorship care plan at the end of their treatment that guides patients if and when they transition back to their primary care or specialty provider for follow-up care.

"There's a very clear lack of communication between patients, oncologists and primary care physicians, which can ultimately have a major impact on our patients' long-term health and well-being, particularly if they are experiencing significant late effects of treatment," said Hill. "It's vital to our patients' long-term survival and our ability to provide guidance to them that physicians better educate patients about what they might experience following treatment and encourage patients to raise any concerns or health issues they experience."

**More information:** Hill-Kayser will present the findings (Abstract #6135) between 1:15 and 5:15 on Monday, June 4, in S Hall A2 at McCormick Place, 2301 S. Lake Shore Drive, Chicago.

Provided by University of Pennsylvania School of Medicine

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