What counts as a potential harm of lung cancer screening? Findings from focus groups with current and recent former heavy smokers in Ontario

Dr. Diego Llovet[1] Dr. Jorge Ginieniewicz[1] Dr. Samanthika Ekanayake[1] Dr. Lawrence Paszat[1, 2]

[1]Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto [2] Institute for Clinical Evaluative Sciences

(Contact information: diego.llovet@sunnybrook.ca)

Background

- Lung cancer is the second most diagnosed cancer and the leading cause of death from cancer in Ontario, with an estimated 8,600 new cases and 6,900 deaths in 2013 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013).
- The National Lung Screening Trial (NLST) showed a 20% reduction in lung cancer mortality among high risk individuals who underwent screening with Low-Dose CT Scan (LDCT) instead of conventional chest x-rays (control) (NLST Team, 2011).
- As a result of the NLST findings, Cancer Care Ontario is recommending lung cancer screening for men and women 55-74 "with a minimum smoking history of 30 pack/years who currently smoke or have quit within the last 15 years and are disease free at the time of screening" (Roberts et al., 2013).
- Screening programs and health care providers are being encouraged to offer adequate and balanced information about the potential harms and benefits of screening for lung cancer in order to facilitate informed decision-making among high risk persons (Woloshin et al., 2012; Wiener, 2013).
- High-risk persons and public health experts may, however, disagree on whether and/or how an event constitutes a "harm" of screening. The "mental models" theory of risk communication suggests that laypersons and experts often rely on different definitions and interpretations of health information (Morgan et al., 2000).
- While false positive results have been identified by public health experts as a potential harm of lung cancer screening (Harris et al., 2013), little is known about how this risk is understood by high-risk individuals.
- Prior qualitative research has shown that, while creating some degree of anxiety, false positive results from mammography are generally not regarded by women as a harm of screening (Silverman et al., 2001; Nekhlyudov et al., 2003). Our study hypothesizes that a similar view may prevail among individuals at high risk for lung cancer.
- Understanding how high-risk persons interpret the risk of false positives and other potential harms is key to communicating effectively with the target population about lung cancer screening.

Objectives

- This study explores how current and recent former heavy smokers in Ontario understand the potential harms of lung cancer screening with LDCT.
- This poster reports specifically on how current and recent former heavy smokers understand and interpret the possibility of receiving a false positive LDCT result.

Methodology

- 3 two-hour focus groups were conducted with 21 current and recent former heavy smokers in Niagara Falls, Toronto and Sudbury in November, 2013.
- Focus group participants were recruited through random digit-dialling by the Institute for Social Research at York University.
- Two focus groups with current heavy smokers: individuals who currently smoke at least one pack of cigarettes per day, or quit within the last 12 months.
- One focus group with recent former heavy smokers: individuals who used to smoke at least 1 pack of cigarettes per day but quit smoking 1-15 years ago.
- Participants: aged 55- 73 with no prior history of lung cancer, 40% female, 60% high-school graduates or lower.
- An experienced moderator presented potential harms of screening and asked participants to offer their views. Potential harms included: 1) false positive results (96.4% of positive LDCT scans are false), 2) allergic reactions to dye (contrast CT scan), 3) pneumothorax, 4) chronic complications from surgery, 5) radiation-induced lung cancer.
- Focus groups were audio-recorded, transcribed and reviewed for accuracy.
- Three qualitative investigators independently coded data using NVivo10 and inductively identified themes.

Results

- The majority of participants agreed that the information about false positive is important and that it should be provided to people considering lung cancer screening with LDCT.
- Several participants disagreed that receiving false positive CT scan results is necessarily harmful because false positives are relatively common with any medical tests.

> *"I've heard of it before, the false alarm with any CAT scan, so it doesn't surprise me. I mean, nothing's perfect, but with further testing they found out that it was none."* (Daniel, Niagara Falls, current heavy smokers)

- Many participants indicated that being told ahead of time of a possible false positive result would help them manage their anxiety and avoid distress.

> *"It would also lessen the chances that you were going to freak out, you know? I mean, if you know there is a chance that you're going to get false positives… I think you need that information, otherwise they're going to come back and say, 'There's something there', and your automatic response is going to be, 'I have cancer.'"* (Lisa, Toronto, recent former heavy smokers)

- One participant said that false alarms "protect" people undergoing screening because a positive result would invite follow-up and treatment, if necessary.

> *"[A false alarm] protects you because it does find a spot, let's say it finds a spot and it's 96% that you don't have anything, you could pursue to see, you know, if that spot is something, and if it is then you can do something about it early."* (Alex, Toronto, recent former heavy smokers)

- Several participants stated that the possibility of receiving a false positive result would not change their mind about getting screened.

> *"I still think [screening is] a good idea. I think I would rather know that it's a false alarm but that there's something there rather than to just let everything go and not do anything [about it]."* (Tracy, Sudbury, current heavy smokers)

- However, some participants indicated that they would be anxious to know whether their positive result is true or false and asked how long this would take.

> *"So if they do see a spot how long from the time they see a spot 'til you know that it's a false alarm or that it's something…I would go crazy. … Mentally I wouldn't be able to... handle that waiting, because in the back of your head you'd be thinking…"* (Tracy, Sudbury, current heavy smokers)

- One participant, who was opposed to the idea of screening from the beginning, was adamant that a 96% false positive rate was too high and made the LDCT a failure.

> *"So this is a 96% failure rate?... As a businessman, if you were going in business and they said to you, you know, 'You can go in business but it's going to be a 96% failure', would you do it?"* (Peter, Niagara Falls, current heavy smokers)

Conclusions and Recommendations

- All participants agreed that they would want to be informed about the possibility of a "false alarm".
- The majority of focus group participants disagreed with the expert concept that false positives are necessarily a harm of screening. In fact, knowing that "false alarms" are possible might help screenees manage their anxiety if they received a positive result.
- Information on false positives may make more sense to high risk individuals if discussed separately from the other potential harms of screening. For example, information on false positives could be used to help describe LDCT as a very sensitive test that often requires undergoing a second test to obtain an intelligible result.
- A clear follow-up plan should be provided to screenees at the same time as they are notified of a positive LDCT result.

References

- Canadian Cancer Society's Advisory Committee on Cancer Statistics (2013). "Canadian Cancer Statistics 2013". Toronto, ON: Canadian Cancer Society.
- Harris, R., Sheridan, S., Lewis, C., Barclay, C., Vu, M., Kistler, C., Golin, C., DeFrank, J., Brewer, N. (2013). "The harms of screening: a proposed taxonomy and application to lung cancer screening", JAMA Internal Medicine, December 9th.
- National Lung Screening Trial Research Team (2011), "Reduced lung cancer mortality with low-dose computed tomographic screening", New England Journal of Medicine, Vol. 365, 5: 395-409.
- Nekhlyudov, L., Ross-Degnan, D., Fletcher, S. (2003). "Beliefs and expectations of women under 50 years old regarding screening mammography", Journal of General Internal Medicine, 18: 182-189.
- Roberts H, Walker-Dilks C, Sivjee K, Ung Y, Yasufuku K, Hey A, et al. (2013) "Screening high-risk populations for lung cancer". Toronto (ON): Cancer Care Ontario; April 18. Program in Evidence-based Care Evidence-based Series No.: 15-10.
- Silverman, E., Woloshin, S., Schwartz, L., Byram, S., Welch, H., Fischhoff, B. (2001). "Women's views on breast cancer risk and screening mammography: a qualitative interview study", Medical Decision Making, 21(3):231-40.
- Wiener, R. and Slatore, C. (2013), "Framing discussions about CT scan screening for lung cancer so that patients see the whole picture", Chest, 144, 6: 1749-1750.
- Woloshin, S. Schwartz, L., Black, W., Kramer, B. (2012), "Cancer screening campaigns – Getting past uninformative persuasion", New England Journal of Medicine, 367, 18: 1677-1679.

Sunnybrook Research Institute

ICES Institute for Clinical Evaluative Sciences

cancer care ontario | action cancer ontario