

Cancer screening barriers and facilitators for under and never screened populations: A mixed methods study



Dionne Gesink^{a,*}, Brooke Filsinger^b, Alanna Mihic^a, Todd A. Norwood^{a,b}, C. Sarai Racey^a, Daniel Perez^c, Joan Antal^b, Paul Ritvo^c, Lee Vernich^a

^a Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada

^b Analytics and Informatics, Cancer Care Ontario, Toronto, Ontario, Canada

^c School of Kinesiology and Health Science, York University, Toronto, Ontario, Canada

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ABSTRACT

Background: Cancer screening is below targets in Ontario, Canada. Our objective was to identify and quantify the barriers and facilitators for breast, cervical and colorectal cancer screening for under and never screened (UNS) residents living in Ontario between 2011 and 2013.

Methods: We used a multi-phased mixed methods study design. Results from thematic analysis of focus group discussions with health care providers and UNS community members were used to develop an online, province-wide, cross-sectional survey to estimate the prevalence of barriers and facilitators for the provincial population. Adjusted prevalence odds ratios and 95% confidence intervals were estimated for UNS compared to regularly screened participants using logistic regression.

Results: Four focus groups were held with health service providers and sixteen with UNS community members. Top barriers and facilitators themed around provider-patient communication, fear and embarrassment, history of physical or sexual abuse, social determinants of health (including low literacy, lack of awareness, and health insurance), symptoms appearing, and family and friends. 3075 participants completed the online survey. Compared to regularly screened participants, UNS had significantly higher odds of reporting: no regular health care provider; not feeling comfortable talking about screening; or the Doctor or Nurse Practitioner not suggesting screening. UNS also had significantly higher odds of reporting the facilitators: the test being less scary/painful or uncomfortable; friend/family insisting on getting screened; starting to have symptoms; or an easier test that could be done at home.

Conclusions: Interventions addressing fear through individual, interpersonal and structural facilitators may increase cancer screening.

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1. Introduction

The gap between targeted and observed cancer screening rates is partly driven by under- and never-screened (UNS) populations [1,2] who are often marginalized, hard-to-reach and seldom heard [3,4]. Some of these groups have been defined by socio-demographic characteristics, including being indigenous [4,5], immigrants [6–9], visible minorities [10], men [1,11], or members of particular religious groups [1,12]. Other groups have been defined by characteristics focused on barriers [13], including living in rural locales [14,15], the uninsured [1,2], the underserved [16], living in crisis [1], living with mental illness [17–19], sexual abuse

survivors [1,20,21] and traditional, complementary and alternative medicine users [1,22]. The diversity and heterogeneity within groups, and the intersectionality between groups [1], reveals complex under- and never- screened populations with cancer screening dynamics that are challenging to navigate.

In Ontario, Canada, breast, cervical and colon cancer screening are below targets [1,8,23] despite being offered free of charge to all residents eligible for screening. The majority of Ontarians are covered by universal health care through the Ontario Health Insurance Program (OHIP). There are also mechanisms by which uninsured residents can access cancer screening without charge; though, the cost of treatment is charged to uninsured individuals. Cancer Care Ontario, an agency of the provincial government mandated to advise the government on cancer and access to care, sends personalized letters inviting eligible Ontarians to participate in cancer screening; specifically, women 50–74 years of age at average risk for breast cancer, women 21–69 years of age at risk for

* Corresponding author at: Dalla Lana School of Public Health, University of Toronto, 155 College St, 6th Floor, Toronto, Ontario M5T 3M7, Canada.
E-mail address: dionne.gesink@utoronto.ca (D. Gesink).

cervical cancer, and men and women 50–74 years of age at average risk for colon cancer. Additionally, personalized letters are sent reminding eligible Ontarians when it is time to return for screening and informing participants of their screening results.

Most women receive mammogram screening for breast cancer through the Ontario Breast Screening Program (OBSP), where appointments can be made directly without a doctor's referral. Women with regular risk and normal results are encouraged to return for mammography every two years. Women 21 years old or older who are, or have been, sexually active can receive cervical screening by making an appointment with a doctor's office or sexual health clinic for a Papanicolaou (Pap) test. Individuals with normal Pap test results are encouraged to return for screening every three years. Asymptomatic individuals with no family history of colon cancer can be screened for colon cancer at home using the fecal occult blood test (FOBT), repeating every two years if results are normal, or screened at hospital using a minimally invasive surgical procedure (usually colonoscopy, endoscopy, or flexible sigmoidoscopy), repeating every 10 years if results are normal.

Our objective was to identify and quantify the barriers and facilitators for breast, cervical and colorectal cancer screening for UNS residing in Ontario, Canada. The results were used to develop key characteristics for subsequent cancer screening interventions.

2. Materials and methods

2.1. Study setting

Ontario is the largest province in Canada by population (13.51 million in 2012 or 40% of Canada's total population), and the second largest province by land area (1,076,395 km²). Ontario comprises multi-cultural, urban, suburban, small city, rural, reserve, remote, and fly-in communities.

2.2. Design

We used a multi-phased mixed methods study design (Fig. 1) [24,25]. Each phase and strand of the study was informed by previous phases and strands. Each strand overlapped the previous and subsequent strand in time. In overview, quantitative data were used to generate maps of breast, cervical and colorectal cancer screening rates, which were interpreted qualitatively. Four communities with low screening rates for all three cancers were

shortlisted for in-depth study [1]. Health care providers in these four communities were interviewed using focus groups. Health care providers could be directors, physicians/clinicians, nurses, counsellors, community health workers, social workers, outreach workers or any other individual working in primary care relating to cancer prevention and detection. Subsequently, community members from groups identified as UNS were targeted for follow-up focus groups to verify the characteristics of, and identify barriers and facilitators for, the under and never screened [1]. Community members were recruited by health care providers. Preliminary focus group results informed and closed questions included in a province-wide cross-sectional survey intended to estimate the prevalence of identified barriers and facilitators for the provincial population. Prevalence estimates were intended to validate and provide a sense of the transferability of the qualitative results, and help prioritize and optimize intervention strategies targeting barriers and facilitators for both the provincial population and specific hard-to-reach groups. The combined knowledge and synergy of the qualitative and quantitative strands was greater than the individual strands independently [24,25]. This study was approved by the University of Toronto Research Ethics Board.

2.3. Mapping

Cancer screening and population data for 2009 were obtained from the Institute for Clinical Evaluative Sciences (ICES). ICES linked administrative health datasets using individual, encrypted health identifiers to identify the population eligible for screening according to age and health status. The registered persons database (RPDB) identified the age-eligible population with linkage to the Ontario Cancer Registry (OCR) to exclude persons with prior cancer diagnoses and health billings (OHIP) and identify relevant prior health events for exclusion. Persons who died during 2009 (RPDB) were also excluded. These data sources are considered high quality and have been used to develop validated algorithms [26].

Specifically, for Pap tests, women aged 30–69 years with no identifiable prior cancer or hysterectomy were screen-eligible. Women aged 30–49 who had completed the Pap test within the recommended time frame were classified as screened. For breast cancer screening mammography, women aged 50–74 years with no prior cancers, bilateral mastectomies, or bilateral breast implants comprised the eligible population. Women 50 years of age and older who had completed both the Pap and mammography tests within the recommended time frame were classified as

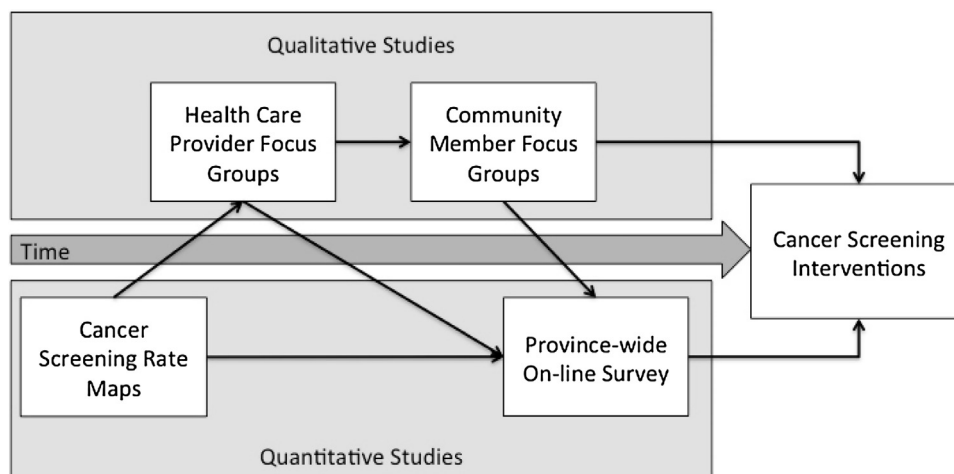


Fig. 1. Multi-phase mixed methods study design, timing and mixing of information (represented by arrows).

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