Cancer screening practices of cancer survivors

Population-based, longitudinal study

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Abstract

Objective To describe cancer screening rates for cancer survivors and compare them with those for matched controls.

Design Population-based, retrospective study with individuals linked across administrative databases.

Setting Ontario.

Participants Survivors of breast (n=11 219), colorectal (n=4348), or endometrial (n=3473) cancer, or Hodgkin lymphoma (HL) (n=2071) matched to general population controls. Survivors were those who had completed primary treatment and were on "well" follow-up. The study period was 4 years (1 to 5 years from the date of cancer diagnosis).

Main outcome measures *Never* versus *ever* screened (in the 4-year study period) for breast cancer, colorectal cancer (CRC), and cervical cancer and *never* versus *ever* received (during the study period) a periodic health examination; rates were compared between cancer survivors and controls. Random effects models were used to estimate odds ratios and 95% CIs.

Results Sixty-five percent of breast cancer survivors were never screened for CRC and 40% were never screened for cervical cancer. Approximately 50% of CRC survivors were never screened for breast or cervical cancer. Thirty-two percent of endometrial cancer survivors were never screened for breast cancer and 66% were never screened for CRC. Forty-four percent of HL survivors were never screened for breast cancer, 77% were never screened for CRC, and 32% were never screened for cervical cancer. Comparison with matched controls showed a mixed picture, with breast and endometrial cancer survivors more likely, and CRC and HL survivors less likely, than controls to be screened.

Conclusion There is concern about the preventive care of cancer survivors despite frequent visits to both oncology specialists and family physicians during the "well" follow-up period.

EDITOR'S KEY POINTS

- The large and growing number of cancer survivors in Canada has led to a shift in perception from cancer being an acute life-threatening disease to it being a chronic disease. Because cancer survivors are often at higher risk of developing new primary cancers, they should receive age-appropriate cancer screening for second primary cancers.
- This population-based, longitudinal study of survivors of breast cancer, colorectal cancer, endometrial cancer, or Hodgkin lymphoma demonstrates a substantial gap between age-appropriate screening for second primary cancers and the observed screening practices among cancer survivors.
- Family physicians, as the principal providers of preventive care, should be aware of the importance of screening for second primary cancers among cancer survivors.

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Dépistage du cancer chez des survivants d'un cancer

Étude longitudinale fondée sur la population

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Résumé

Objectif Déterminer les taux de dépistage du cancer chez les survivants d'un cancer par rapport à ceux de témoins appariés.

Type d'étude Étude rétrospective stratifiée avec appariement des sujets au moyen de bases de données administratives.

Contexte L'Ontario.

Participants Des survivants du cancer du sein (n=11 219), du cancer colorectal (n=4348), du cancer de l'endomètre (n = 3473) ou d'un lymphome Hodgkinien (LH) (n=2071), appariés à des témoins de la population générale. Étaient considérés survivants ceux qui avaient complété le traitement primaire et avaient un suivi favorable. La période de l'étude était de 4 ans (entre 1 et 5 ans après la date du diagnostic).

Principaux paramètres à l'étude Le fait d'avoir eu *au moins un*, ou *aucun* dépistage du cancer du sein, du cancer colorectal (CCR) et du cancer du col durant les 4 ans de l'étude, et d'avoir eu *au moins un*, ou *aucun* examen de santé périodique durant cette même période; les taux des survivants du cancer ont été comparés à ceux des témoins. On a utilisé des modèles à effets aléatoires pour estimer les rapports de cote et les IC à 95%.

Résultats Parmi les survivants du cancer du sein, 65% n'ont eu aucun dépistage du CCR et 40%, aucun pour le cancer du col. Environ 50% des survivants du CCR n'ont eu aucun dépistage pour le cancer du sein ou celui du col. Trente-deux pour cent des survivants du cancer de l'endomètre n'ont jamais été dépistés pour le cancer du sein et 66% n'ont jamais été dépistés pour le CCR. Parmi les survivants du LH, 44% n'ont eu aucun dépistage du cancer du sein, 77% n'en ont eu aucun pour le CCR et 32%, aucun pour le cancer du col. La comparaison avec les témoins appariés donnait une image mixte, les survivants des cancers du sein et de l'endomètre étant plus susceptibles tandis que ceux du CCR et du LH étaient moins susceptibles d'avoir des dépistages que les témoins.

Conclusion Les soins préventifs des survivants du cancer suscitent des inquiétudes malgré de fréquentes visites auprès d'oncologues et de médecins de famille au cours de la période de rémission.

POINTS DE REPÈRE DU RÉDACTEUR

- Le nombre de plus en plus élevé de survivants du cancer au Canada fait en sorte que le cancer n'est plus perçu comme une maladie aiguë éventuellement mortelle, mais plutôt comme une maladie chronique. Parce que les survivants d'un cancer sont souvent plus à risque de développer de nouveaux cancers primaires, ils devraient faire l'objet des dépistages recommandés pour leur âge pour d'autres cancers primaires.
- Cette étude longitudinale stratifiée auprès de survivants du cancer du sein, du cancer colorectal, du cancer de l'endomètre ou du lymphome hodgkinien a montré qu'il existe une différence importante entre la façon recommandée de dépister d'autres cancers primaires selon l'âge et celle observée chez les survivants d'un cancer.
- En tant que principal responsable des soins préventifs, le médecin de famille devrait être conscient de l'importance du dépistage de nouveaux cancers primaires chez les survivants d'un cancer.

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There is substantial interest internationally in the health care needs of cancer survivors.[1,2] Their large and growing number is a result of both improved cancer survival rates, and growth and aging of the population leading to increased incidence of cancer. Approximately 3% of the population in developed countries are cancer survivors.[1,2] In Canada, there are more than three-quarters of a million 15-year cancer survivors, and this number is expected to increase dramatically. It is estimated that 1 in 40 Canadian men and 1 in 35 Canadian women have had a cancer diagnosis in the previous 15 years.[3]

This increase in the prevalence of cancer survivors has led to a shift in perception from cancer being an acute life-threatening disease to it being a chronic disease in which most will die from causes other than their cancer.[1,4] Accordingly, the concept of cancer "survivorship" now emphasizes the importance of general preventive health care.[1,5] Because cancer survivors are often at higher risk of developing new primary cancers, all patients with early-stage cancer should receive age-appropriate cancer screening for second primary cancers.[6] Little is known about cancer screening practices of adult cancer survivors in Canada. The objective of this study was to describe age- and sex-appropriate screening rates for second primary cancers (ie, screening for cancers other than the cancer for which the patient has been diagnosed) of population-based cohorts of adult cancer survivors and compare them with those of matched controls.

METHODS

We conducted a population-based, retrospective, longitudinal case-control study of survivors of breast cancer, colorectal cancer (CRC), endometrial cancer, or Hodgkin lymphoma (HL) and age-, sex-, and geography-matched controls in Ontario. Ethical approval was obtained from the Institute of Clinical Evaluative Sciences Research Ethics Board in Toronto, Ont.

Cancer survivors and controls

Cancer survivors were identified through the Ontario Cancer Registry and included all patients diagnosed with one of the cancers being studied who were in the Registered Persons Database (which contains demographic information) and eligible for the Ontario Health Insurance Plan (OHIP), the health insurance plan available to all residents of Ontario. The number of years included was determined for each cancer cohort in order to attain a sufficient sample size and at least 5 full years of follow-up after diagnosis. For all 4 cancer cohorts, exclusion criteria were established to identify initial cancer survivors who were without recurrence and on "well" follow-up within the first year after diagnosis. Patients were excluded if they had previous primary cancers; if they did not receive primary curative surgery or, in the case of HL, chemotherapy; or if they had died, had evidence of advanced cancer, or had evidence of a possible recurrence within the first year after diagnosis. For all 4 cancer cohorts, patients were censored in each of 4 subsequent follow-up years if they were no longer eligible for OHIP, they developed a new primary cancer, or they experienced a cancer recurrence (based on OHIP fee codes for chemotherapy, radiation therapy, or surgery). Exclusion and censoring criteria were set conservatively to identify only cancer patients who were on "well" follow-up. Detailed descriptions of the study cohorts have been published previously.[7-9]

For each cancer survivor, an initial pool of controls from the general population was chosen from the Registered Persons Database, and the individuals were assigned the same index date as the cancer survivor. The pool was further refined by excluding people who were diagnosed with cancer within 1 year of the index date, who were not OHIP-eligible for at least 1 year after the index date, or who died before the index date. In order to increase the power of the study, from this final pool, 5 controls—matched on year of birth, sex, and region (Local Health Integration Network) to the case—were randomly chosen.

Data sources and measures

Scrambled anonymized health care numbers were used to link individuals across the databases. The Ontario Cancer Registry was used to identify new primary cancers, and vital statistics were used to identify deaths. Whether breast cancer screening had occurred was determined for those aged 50 to 79 using OHIP records for mammograms and the Ontario Breast Screening Program database. Occurrence of cervical cancer screening was determined for those aged 20 to 69 using OHIP records for Papanicolaou tests and CytoBase, a database which captures approximately 90% of cervical cytology in Ontario. Occurrence of screening for CRC was determined for those aged 50 to 74 using OHIP records for colonoscopy, sigmoidoscopy, barium enema, or fecal occult blood testing (FOBT). Whether subjects had received periodic health examinations was determined by the OHIP fee code A003 or diagnostic code 917.

The study period was 4 years starting 1 year from the date of cancer diagnosis to 5 years from the date of diagnosis, or sooner if censored. All screening procedures were classified as *never* versus *ever* screened during the 4-year study period. The second primary cancer screening procedures studied were breast cancer survivors screened for CRC and cervical cancer; female CRC survivors screened for breast cancer and cervical cancer; endometrial cancer survivors screened for breast

cancer and CRC (endometrial cancer survivors are not candidates for cervical cancer screening because most of these patients have had hysterectomies); HL survivors screened for CRC, with female HL survivors also screened for breast and cervical cancer. All cancer survivors were studied for periodic health examinations.

Analysis

Descriptive statistics were calculated for frequency of breast cancer screening, CRC screening, cervical cancer screening, and periodic health examinations for cancer survivors and matched controls. We used random effect models as an alternative to conditional logistic regression to estimate odds ratios and 95% CIs.[10] Analyses were performed using SAS, version 9.2.

RESULTS

Table 1 presents the characteristics of the cancer cohorts. Cancer cohorts were assembled between 1996 and 2000, except for the HL cohort, which started in 1992 in order to include more survivors because of the relatively low incidence. Descriptions of demographic and disease characteristics of the cohorts have been published previously.[7-9]

Table 2 presents the proportion of cancer survivors and controls who were never screened (ie, did not receive the age- and sex-appropriate screening maneuver during the 4-year study period). Approximately two-thirds of breast cancer survivors were never screened for CRC, one-third were never screened for cervical cancer, and one-third had had no periodic health examination during the 4 years. For all screening tests breast cancer survivors were significantly ($P<.0001$) less likely than matched controls to have never been screened, although the absolute differences were small (eg, 65.3% never screened vs 67.7% never screened, respectively, for CRC screening).

Approximately half of CRC survivors were never screened for breast cancer or cervical cancer, and had not had a periodic health examination during the 4-year study period. Survivors of CRC were significantly more likely than matched controls to never have been screened for breast cancer ($P<.005$) or to never have had a periodic health examination ($P<.0001$), although the absolute differences were small (eg, 46.4% never screened vs 42.0% never screened, respectively, for breast cancer screening).

For endometrial cancer survivors, approximately one-third were never screened for breast cancer and two-thirds were never screened for CRC. They were significantly ($P<.005$) less likely than matched controls to be never screened for CRC, although the absolute differences were small (eg, 65.6% never screened vs 68.8% never screened, respectively, for CRC screening). There were no significant differences between cancer survivors and controls for periodic health examinations, with approximately one-third of both groups having not had periodic health examinations during the 4-year study period.

Approximately 40% of HL survivors were never screened for breast cancer and never had periodic health examinations, one-third were never screened for cervical cancer, and three-quarters were never screened for CRC during the 4-year study period. They were significantly ($P=.02$) more likely than matched controls to never have been screened for CRC or have had periodic health examinations.

DISCUSSION

In this population-based study of cancer survivors we found a substantial gap between recommended age-appropriate screening for second primary cancers and observed cancer screening. Overall, between one-third and more than three-quarters of cancer survivors were never screened during the 4-year study period. Comparing cancer survivors and matched controls from the general population, we see a mixed picture. Breast cancer and endometrial cancer survivors were more likely than matched controls to be screened, while CRC and HL survivors were less likely than matched controls to be screened. In most instances the absolute differences were small, with statistical significance likely reflecting the large sample size.

While it is widely recognized that cancer screening rates for the general population are inadequate,[11] this

Table 1. Characteristics of cancer cohorts

CHARACTERISTIC	COHORT*			
	BREAST CANCER	CRC	ENDOMETRIAL CANCER	HL
No. of men	None	1833	None	1134
No. of women	11 219	2515	3473	937
Calendar years of initial cancer diagnosis	1998 to 1999	1996 to 1999	1996 to 2000	1992 to 2000
Mean (SD) age, y	60.1 (13.7)	62.4 (11.0)	63.0 (11.4)	35.4 (17.1)

CRC—colorectal cancer, HL—Hodgkin lymphoma.
*Complete descriptions of breast, endometrial, and HL cancer cohorts are published elsewhere.[7-9]

Table 2. Comparison of cancer screening among cancer survivors and controls: *Proportion never screened during the 4-year study period.*

CANCER SURVIVORS AND CONTROLS	SCREENING MANEUVERS			
	BREAST CANCER SCREENING*	CRC SCREENING†	CERVICAL CANCER SCREENING‡	PERIODIC HEALTH EXAMINATION
Breast cancer	NA			
• Cases, N		6530	726	11 219
• Controls, N		32 517	34 228	56 014
• Never screened				
- Cases, n (%)		4262 (65.3)	2673 (39.7)	3770 (33.6)
- Controls, n (%)		22 025 (67.7)	16 639 (48.6)	21 381 (38.2)
• OR (95% CI)		1.12§ (1.06-1.18)	1.48§ (1.40-1.56)	1.23§ (1.18-1.28)
CRC		NA		
• Cases, N	1489		1071	4348
• Controls, N	7441		5527	21 740
• Never screened				
- Cases, n (%)	691 (46.4)		574 (53.6)	2028 (46.6)
- Controls, n (%)	3123 (42.0)		2883 (52.2)	8244 (37.9)
• OR (95% CI)	0.83‖ (0.74-0.93)		0.94 (0.82-1.08)	0.69§ (0.65-0.74)
Endometrial cancer			NA	
• Cases, N	2713	2452		3473
• Controls, N	13 993	12 281		17 357
• Never screened				
- Cases, n (%)	872 (32.1)	1608 (65.6)		1358 (39.1)
- Controls, n (%)	5900 (42.2)	8447 (68.8)		6699 (38.6)
• OR (95% CI)	1.60§ (1.46-1.75)	1.16‖ (1.06-1.27)		0.98 (0.91-1.06)
HL				
• Cases, N	151	362	605	2071
• Controls, N	762	1835	3025	10 229
• Never screened				
- Cases, n (%)	66 (43.7)	279 (77.1)	196 (32.4)	902 (43.6)
- Controls, n (%)	307 (40.3)	1306 (71.2)	968 (32.0)	4195 (41.0)
• OR (95% CI)	0.86 (0.60-1.25)	0.73¶ (0.56-0.96)	0.98 (0.80-1.19)	0.89¶ (0.81-0.99)

CRC—colorectal cancer, HL—Hodgkin lymphoma, OR—odds ratio, NA—not applicable.
*Among subjects aged 50 to 79 y.
†Among subjects aged 50 to 74 y.
‡Among subjects aged 20 to 69 y.
§$P < .0001$.
‖$P < .005$.
¶$P = .02$.

study is the first to demonstrate that Canadian cancer survivors are not being screened despite numerous interactions with the health care system, and numerous encounters with providers who are knowledgeable about cancer screening principles (family physicians and oncologists). Several American studies have identified a similar situation.[12-15]

The cancer survivors in this study were those on "well" follow-up, with no evidence of disease, and were likely to be long-term survivors. Hence, for these patients, cancer screening is arguably one of the most important cancer-related maneuvers for early diagnosis. We studied years 2 to 5 following the cancer diagnosis because this reflects the period when aggressive curative treatment is over but continued intensive follow-up means that cancer survivors have many encounters with the health care system. As we have reported previously, these same cancer patients have frequent visits to both oncology specialists and family physicians.[7-9] For example, more than 80% of breast cancer survivors saw

a combination of family physicians and oncologists with an average of 7 family physician visits plus 4 oncology visits in the second year after diagnosis.[7] Similarly, CRC survivors had an average of 10 family physician visits per year compared with an average of 7 visits for the general patient population older than 65 years of age in Ontario.[16]

The periodic health examination was included as a measure of general preventive health care. Overall, more than one-third of cancer survivors and controls never had a periodic health examination during the 4-year period. Similar to the results for cancer screening, breast cancer survivors were significantly more likely, and CRC survivors were significantly less likely, than controls to have had at least 1 periodic health examination during the 4 years.

The particularly low rate of CRC screening for both HL cancer survivors and matched controls might reflect the earlier years of the study period for those cohorts, when CRC screening recommendations were in flux.[17,18] Nevertheless, these low rates are consistent with the findings of other studies of the Ontario population.[11,19]

These findings raise concern about the preventive care provided to cancer survivors. Despite many cancer-focused encounters with the health care system, rates of screening for second primary cancers and periodic health examinations are inadequate. There are 2 possible explanations for these findings. The first is that for survivors and providers, the cancer diagnosis is viewed as the principal health care concern: they have not yet fully realized that substantial improvements in cancer survival rates warrant refocusing attention on preventive care, including screening for second primary cancers. A second explanation is that there is uncertainty among survivors and providers as to who is responsible for preventive care. For example, studies have shown that there is a mismatch between the expectations of patients and those of oncologists regarding who is responsible for cancer screening: two-thirds of patients, but only one-quarter of oncologists, expect oncologists to be substantially involved in cancer screening. However, oncologists, survivors, and family physicians do agree that it is the responsibility of family physicians.[20] Similarly, there is uncertainty over who is primarily responsible for care during the follow-up period.[21,22] This uncertainty might lead to problems of continuity and comprehensiveness of care.[1] This could potentially be ameliorated by incorporating preventive care into all follow-up programs offered to cancer survivors, regardless of whether they are based in cancer care or in primary care settings. There is now a greater recognition of the health care needs of cancer survivors after active treatment is completed—particularly the importance of preventive care and general health care. The shift in focus from acute cancer care to chronic survivorship care warrants that survivors and family physicians understand the importance of screening for second primary cancers.

Limitations

The principal limitation of this study is the recognized problem with administrative health databases of the potential for misclassification of procedures such as mammograms and colonoscopies as screening procedures rather than diagnostic procedures. This misclassification would lead to an underestimation of the proportion never screened, as some of the procedures included might have been for diagnostic rather than screening purposes. Conversely, for CRC there is a risk of overestimation of those never screened because of potential under-reporting of FOBT. However, the methods we have used here are the same as those used by Cancer Care Ontario to capture CRC screening.[11] In addition, it could be that CRC screening rates have now improved with the introduction of a population-based screening program in Ontario.

We took the conservative approach of classifying screening into *never* versus *ever*. However, cancer screening recommendations for cervical, breast, and colorectal cancers all state a time interval. For example, both screening mammograms and FOBT are recommended every 2 years in Ontario, while Pap test recommendations vary depending on the presence or absence of positive test results. Thus, for all the screening maneuvers we studied, the proportion of subjects not receiving age-appropriate cancer screening is likely an underestimate when frequency of screening is taken into account.[18]

Conclusion

A substantial proportion of breast cancer, CRC, endometrial cancer, and HL survivors are not receiving age- and sex-appropriate screening for second primary cancers. Comparison with matched controls showed a mixed picture, with breast and endometrial cancer survivors more likely, and CRC and HL survivors less likely, than controls to be screened. Nevertheless, this raises concern about the preventive care of cancer survivors despite frequent visits to both oncology specialists and family physicians during the "well" follow-up period.

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Contributors

Dr Grunfeld participated in data analysis and interpretation and wrote the manuscript. **Dr Moineddin** and **Ms Gunraj** participated in data analysis and interpretation. All authors contributed to the concept and design of the study and to revision, contribution of intellectual content, and final approval of the manuscript.

Competing interests

None declared

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