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Original article

Does a dedicated program for young breast cancer patients affect the likelihood of fertility preservation discussion and referral?

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ABSTRACT

Purpose: To assess whether a dedicated program for young breast cancer patients, including a nurse navigator, improves the frequency of: a) fertility discussion documentation and b) fertility preservation (FP) referrals.
Methods: A retrospective chart review and prospective survey were undertaken of breast cancer patients diagnosed at age 40 or younger between 2011 and 2013 who received adjuvant or neo-adjuvant chemotherapy at two academic cancer centers in Toronto, Canada. The Odette Cancer Centre (OCC) has a dedicated program for young breast cancer patients while Princess Margaret Cancer Centre (PM) does not. Patient demographics, tumor pathology, treatment and fertility discussion documentation prior to systemic chemotherapy administration were extracted from patient records. Prospective surveys were administered to the same cohort to corroborate data collected.
Results: Eighty-one patient charts were reviewed at both OCC and PM. Forty-seven and 49 at OCC and PM returned surveys for a response rate of 58% and 60% respectively. Chart reviews demonstrated no difference in the frequency of fertility discussion documentation (78% versus 75% for OCC and PM, $p = 0.71$); however, surveys demonstrated higher rates of recall of fertility discussion at OCC (96% versus 80%, $p = 0.02$). A greater proportion of women were offered FP referrals at OCC, as observed in chart reviews (56% versus 41%, $p = 0.09$), and surveys (73% versus 51%, $p = 0.04$). Time to initiation of chemotherapy did not differ between women who underwent FP and those who did not.
Conclusion: A dedicated program for young breast cancer patients is associated with a higher frequency of FP referrals without delaying systemic therapy.

Background

An important concern for young women with early-stage breast cancer is future fertility [1]. Many women will require adjuvant systemic chemotherapy [2], which often has a detrimental effect on fertility [1]. While adjuvant tamoxifen is not toxic to the ovary, the need to take this drug for several years, during which time pregnancy is contraindicated [3], results in further fertility reduction due to the normal effects of aging. With increasing numbers of women having children at later ages, when natural fertility is already in decline [4], these issues have become increasingly relevant.

Recognizing the importance of this problem, the American Society of Clinical Oncology (ASCO) put forth guidelines in 2006 recommending discussion of the risk of infertility as a consequence of cancer treatment, and an offer of referral for consideration of fertility preservation (FP) for all newly diagnosed cancer patients of child-bearing age [5]. These guidelines further endorse documentation of these discussions [5]. Updated guidelines in 2013 continue these recommendations [6].

Despite increasing recognition of the importance of fertility issues to young breast cancer patients, survivors often do not recall

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having had a fertility discussion with their oncologists [7,8]. Even in studies done years after the original 2006 ASCO guidelines, survivors often report that either that they were not informed of the effects treatment might have on their fertility [9–12], or that they needed to initiate FP discussions prior to their treatment [13]. Documentation of fertility discussion has also been reported to be sub-optimal, as in a recent study only 26% of women had documented fertility risk discussions in their medical record [14]. These data suggest that strategies are necessary to improve these deficits in care. A dedicated program for cancer patients of reproductive age that includes a nurse navigator is one intervention that could potentially increase the frequency of fertility discussion and FP referral.

At the Odette Cancer Centre (OCC) in Toronto, Ontario, 'PYNK: Breast Cancer Program for Young Women' has been operational since 2008 [15]. The first of its kind in Canada, this program provides specialized oncology services for women diagnosed with breast cancer at age 40 or younger, in an effort to effectively address the unique medical and psychosocial challenges this patient population faces, including possible loss of fertility. A key component of this program is a dedicated nurse navigator, one of whose major functions is to implement consistent management for these women, as there are multiple staff physicians and trainees caring for these women within each subspecialty. The nurse navigator screens referrals to the cancer center, contacts all women aged 40 years or less prior to or at their initial appointment and follows these women during diagnosis, treatment and beyond. In addition to expediting tests and consultations, and providing ongoing support, she raises age related issues including fertility, genetics and sexual health. The navigator documents all her activities and services in the nursing section of the electronic patient record.

We hypothesized that the presence of a dedicated program for young breast cancer patients and a nurse navigator would be associated with an increased frequency of fertility discussions prior to initiation of adjuvant or neo-adjuvant systemic therapy. Due to more discussions and increased awareness of best practices among oncologists, we anticipated an increase in documentation of such discussions by the physicians as well as an increase in referral to FP services.

Methods

Study design

A comparative cohort study comprising a retrospective chart review and prospective survey was undertaken, with OCC forming the experimental group, and Princess Margaret Cancer Centre (PM), which does not have a dedicated program for younger women, forming the control group. Electronic patient records (EPR) were retrospectively reviewed at both sites. The same cohort of women was prospectively sent surveys to corroborate information identified in EPR. Both cancer centers are academic, tertiary medical centers affiliated with the University of Toronto in Toronto, Ontario, Canada. OCC is in a central but residential part of the city while PM is located in the city's downtown core.

Patient population

All female, adult patients, age forty years or younger, diagnosed between January 2011 and December 2013 with non-metastatic invasive breast cancer who received adjuvant or neo-adjuvant systemic chemotherapy were included in the study. OCC patients were identified from the PYNK database and pharmacy records were used to identify eligible women at PM. Pharmacy records provide an accurate assessment of all patients who receive chemotherapy, as these records are required for the cancer center to be reimbursed in our single payer government-funded health care system. Patients who received only endocrine therapy (10% of patients with non-metastatic cancer in the PYNK database) were excluded. This was because it was not possible to identify a complete cohort of these patients at PM, as pharmacy records did not track endocrine therapy administration during our study period. December 2013 was used as the end date, as PM implemented an Adolescent and Young Adult program in 2014 to address issues such as fertility preservation. January 2011 was used as the start date, as the PYNK program was introduced at the OCC in 2008 and an average of 3 years was anticipated for complete implementation of the program.

Data collection

All variables of interest were extracted from the cancer center EPR; no additional EPR systems were used (such as the fertility clinic). Data extracted included: demographics; tumor stage; dates of diagnosis, surgical consult, primary surgery and first dose of chemotherapy; endocrine therapy usage; documentation of fertility discussion and the health care provider conducting the discussion; and documentation of FP referral, and consultation.

The mailed survey consisted of a 15-item multiple-choice questionnaire designed to obtain the 'true' fertility discussion and referral data to which the documentation in the EPR could be compared. Demographic data were also requested to determine the degree to which survey participants were representative of the larger cohort whose charts were reviewed. Responses were requested within eight weeks of survey receipt. Reminder cards were not mailed.

Data analysis

Descriptive statistics were used to characterize baseline patient variables, with categorical variables reported as proportions and continuous variables as medians and ranges. Chi-squared testing was used to compare categorical variables and t-tests for continuous variables. Statistical analyses were performed using SPSS version 21 (SPSS, Chicago, IL). Statistical significance was two-tailed and defined as p-value < 0.05. No adjustment was made for multiple testing.

Results

Patient characteristics

Eight-one patients were identified at both OCC and PM. Baseline characteristics are listed in Table 1. Overall the cohorts were well matched with the exception of a greater proportion of nulliparous women at PM compared to OCC. Within these cohorts, 47 and 49 women at OCC and PM returned surveys, for a response rate of 58% and 60% respectively. Survey respondents were similar to the larger groups with respect to demographic variables.

Fertility discussions

Chart reviews identified that for 63 (78%) women at OCC and 61 (75%) women at PM ($p = 0.71$) there was documentation of a fertility discussion prior to chemotherapy administration (Table 2). However, surveys indicated that a higher proportion of women recalled having fertility discussions prior to initiation of adjuvant systemic therapy, with significantly more women at OCC than at PM recalling discussions (96% versus 80%, p-value $= 0.02$). Of the two and ten women at OCC and PM who did not recall having a