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Title: What are the patterns of referral and uptake of BRCA testing of eligible women with ovarian cancer in New Zealand?

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Introduction:

Ovarian cancer is a serious disease; though uncommon (accounting for only 4% of cancers in the western world), it is the 4th leading cause of cancer deaths in women. As with many cancers there is a well-established hereditary component. Mutations in germline BRCA 1 and BRCA 2 genes account for 11.7- 16.6% of all high-grade epithelial cancers. The risk of developing an ovarian cancer over a patient's lifetime increases for women with a BRCA 1 and BRCA 2 mutation from 1.3% to 18-40%. It is therefore important to be aware of the BRCA status of a patient with ovarian cancer in terms of informing both treatment options and management of inherited cancer risks in patients and their families.

Recent international studies suggest there is a wide variation in referral and uptake of testing for BRCA in women with ovarian cancer, however only half, or even less, of eligible women are being referred to genetic services. New Zealand guidelines recommend referral for all women diagnosed with a high-grade serous ovarian cancer. Thus far no data regarding national referral rates has been gathered in New Zealand. Our study aims to fill this gap.

Aim + Impact

The aim of this audit was to determine the rate of referral and uptake to a genetic service in New Zealand of women with a diagnosis of high-grade serous ovarian, fallopian tube or primary peritoneal cancer. The secondary aims were to determine the timeliness of referrals, the efficiency of the referral and testing process, the proportion of women who were offered and received BRCA mutation testing and, of those, the proportion with a germline BRCA mutation. This data will help identify barriers to referral as well as problem areas in the referral process. Furthermore it will provide baseline data for comparison in future studies.

Method:

This was a multi-centre retrospective audit using data collected in Dunedin, Christchurch, Wellington and Auckland. Eligible cases were identified from each centre's gynaecological oncology Multi-Disciplinary Meeting (MDM) database. Eligible women were newly diagnosed

with a high-grade serous epithelial ovarian, fallopian tube or primary peritoneal cancer between January 01 2015 and 31 December 2016. Relevant data was collated from the MDM databases, electronic medical notes and genetic services databases.

Results

Our study included 245 women of whom 238 were eligible for referral. 158 (66.4%) were referred to genetic services. 78 (32.8%) of eligible women were not referred. Two had unknown status. The majority (64.6%) of referrals were made by Medical Oncologists, with remaining referrals made by a range of other clinicians. No statistically significant difference was observed in referral rates between centres, nor was any difference found in the proportion of Māori (14/21, 65%) vs non-Māori (145/217, 67%) referred. Of the women referred, 131 (82.9%) were offered germline BRCA mutation testing. The majority of those referred but not subsequently offered testing did not met testing criteria i.e. were over 70 and/or had no family history of breast or ovarian cancer. 125 women proceeded with the test, with 123 (93.9%) results recorded. Positive germline BRCA mutations were found in 19 (15.4%) women (13 BRCA 2 and 6 BRCA 1).
Of the 78 women not referred, 47/78 (60.7%) were over 70 years of age at diagnosis. 72/78 (92.3%) had no, or unknown, family history. Furthermore 57.7% of those not referred were deceased within 2yrs of diagnosis compared to 33% of the overall study population.

Conclusions

The overall referral rate (66%) for 2015-2016 for women with a high-grade serous ovarian, fallopian tube or primary peritoneal carcinoma is encouraging when compared to international studies, which found referral rates ranging from 14.5-51.7%. However, there is still approximately one third of the eligible population not being referred. This group tends to be older, more unwell and less likely to have family or personal history of breast or ovarian cancer. Given the limited information available for many of these women, further investigation into the exact reasons they were not referred is required. In addition, the study suggests that having no systematic referral process may impact referral rates. This could result in women who should have been referred, being missed. It is recommended that future studies explore in depth the reasons women were not referred, or, if referred, not offered testing.

Following this, new initiatives aimed at increasing the referral and ultimately the testing rate can be trialed so that as many women and their families as possible can benefit from knowledge of their BRCA status.