LETTER TO JMG

Genetic counselling for familial breast and ovarian cancer in Ontario

A Andermann, S A Narod

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Advances in molecular medicine and increasing attention of the media to clinical developments in genetics have spurred the demand for genetic counselling services for several conditions, most notably for hereditary cancers.[1 2] Genetic counsellors in the Canadian province of Ontario serve a population of 11.7 million, of whom approximately 85% live in urban areas and 15% live in rural areas.[3] The costs of most genetic counselling and related health activities in Ontario are covered by the provincial health plan (OHIP). In almost all cases, block funding is provided by the Ontario Ministry of Health to support genetic counselling services in the hospital setting. There are no private genetic services offered and there is no patient co-payment. Currently, special funds are allocated for cancer genetics services, in addition to funds provided for other genetics services, although an individual genetic counsellor may provide services in both domains. We conducted a descriptive survey of genetic counselling activities in 27 centres in Ontario, Canada to determine the relative distribution of genetic consultations by medical condition, under the current health care system.

METHODS

For the purposes of this study, a genetic counsellor was considered to be a health care provider, practising in a hospital setting, whose primary role was to provide genetic assessment and counselling. A provisional list of all Ontario genetic counsellors was compiled by searching the 2001 membership directories of the Canadian Association of Genetic Counsellors (CAGC, 2001) and of the American National Society of Genetic Counselors (NSGC, 2001). In addition, we telephoned all clinics on the CAGC list of Canadian Genetics Clinics and clinic administrators were asked to provide the names of all people providing genetic counselling in their centre. In addition, a "snowball" technique was used to ascertain genetic counsellors not identified by the first two methods, that is, a request was included on the questionnaire to list the names of colleagues who also provided genetic counselling in their centre. Genetic counsellors who had moved (n=12), who were on maternity leave (n=6), or who were no longer seeing patients (n=2) were excluded.

The study questionnaire asked for the number of genetics appointments seen by each genetic counsellor in the last two months, and for the percentage of these appointments that dealt with each of the following seven categories: infertility; preconceptional and prenatal diagnosis; paediatric conditions; breast and ovarian cancer; colon cancer; other cancers; other adult conditions. The questionnaire was initially sent by e-mail in October 2001, with a reminder by e-mail sent to non-responders three days later, and a reminder phone call to the remaining non-responders the following week. For the majority of respondents, the exact number of appointments was given and this number was used in the calculations. The remaining respondents provided a range of appointments (that is, from 1 to 25, 26 to 50, etc) and the midpoint of the range was used. Therefore the final results are approximate, but are based to a large extent on exact figures. For each respondent, the number of appointments for each type of condition was estimated as the product of the number of appointments and the percentage of appointments relating to each condition. These figures were used to calculate the overall percentage of appointments according to the type of condition for all respondents combined.

RESULTS

Questionnaires were sent to 74 genetic counsellors, of whom 62 responded (response rate 84%). There was at least one respondent from 26 of the 27 genetic centres in the province (the exception was the Windsor Essex County Hospital). Six of the respondents (10%) said that they were the only person who provided genetic counselling in the centre. Overall, 55% (n=34) had an MSc (or other Master's degree) in genetic counselling, 34% (n=21) were nurses with training in genetic counselling, and 27% (n=17) had other qualifications. Other qualifications included a Bachelor's degree in biology, psychology, or genetics (n=8), or a Master's degree in education, nursing, or genetics (n=7). One MD geneticist was included in the sample because he was responsible for all genetic counselling at his centre. Of the sample, 27% (n=17) were Canadian certified genetic counsellors and 19% (n=12) were American certified genetic counsellors.

Key points

- The demand for genetic counselling for the evaluation of familial cancer risk has grown steadily over the last decade. To evaluate the proportion of genetic counselling services which is now devoted to hereditary cancer syndromes, we conducted a province wide, questionnaire based survey of all genetic counsellors and related practitioners in Ontario, Canada.
- A total of 3100 genetic consultations were reported by 62 genetic counsellors during a two month period in 2001; 45% (n=1400) were for preconceptional or prenatal diagnosis, 22% (n=700) were for breast or ovarian cancer, 5% were for other adult cancers (n=150), and 14% (n=420) were for the evaluation of paediatric conditions. Hereditary cancers represented approximately half of the 1700 consultations which were not directly related to reproductive decisions.
- The breast-ovarian cancer syndrome was the number one reason for consultation about non-reproductive issues. Each year, an estimated 4200 genetic consultations are performed for breast or ovarian cancer in Ontario, representing one of every 1400 women in the population. In Ontario, hereditary cancers have now surpassed all paediatric conditions combined in demand for genetic counselling time.

Respondents reported a total of 3100 appointments during the previous two months, or an average of 6.25 appointments per counsellor per week. Sixty-eight percent (n=42) of respondents gave a specific number of genetics appointments, and 32% (n=20) provided a range. Fifty-three percent (n=33) completed from one to 50 consultations, 41% (n=25) completed 51 to 100 consultations, and 6% (n=4) completed more than 100 consultations. The majority of appointments were for prenatal diagnosis (45%, n=1400), for breast and ovarian cancer (22%, n=700), or for paediatric conditions (14%, n=420). Consultations for cancer of all types accounted for 27% (n=850) of all genetics clinic appointments. Of these, 82% (n=700) were for the evaluation of risk for breast and ovarian cancer, 14% (n=120) were for colon cancer, and 4% (n=30) were for other cancers.

A total of 1400 consultations were conducted to facilitate reproductive decisions. Of the 1700 consultations which were not for reproductive purposes, 50% (n=850) of appointments were for hereditary cancers and breast-ovarian cancer was the number one reason for consulting a genetic counsellor (41%, n=700).

Half of the genetic counsellors (n=31) saw no cases of hereditary cancer. Of those who did, 32% (n=10) saw only cancer patients, and 10% (n=3) saw predominantly cancer patients (that is, more than 80% of consultations); 35% of counsellors (n=11) spent less than a quarter of their time on hereditary cancer.

DISCUSSION

We believe that ours is the first comprehensive, population based survey of cancer genetics counselling activity. We have attempted to contact all genetic counsellors in the province, regardless of specialty, whereas previous studies have focused on cancer genetics centres. Studies of cancer genetic services in France and the United Kingdom have shown that there is a large demand for such services, especially in the area of breast cancer genetics.[4–6] According to a survey of North American genetic counsellors, cancer genetics is among the top three most commonly cited specialty areas.[7] We estimate that there are approximately 4200 consultations conducted for breast-ovarian cancer each year in Ontario, or one for every 1400 women in the population. Among genetic counsellors, hereditary cancer, and hereditary breast and ovarian cancer in particular, has surpassed paediatric genetics in terms of the annual number of clinical assessments. Other health care providers, including paediatricians, obstetricians, and other physicians, also provide genetics services to patients, but these are not the subject of the present report. Similarly, medical oncologists, surgeons, and other physicians may offer advice relating to breast and ovarian cancer risk. Our survey pertains only to genetic counsellors in a single province of Canada, but it is likely that these observations reflect similar trends elsewhere in North America.

Because of the high proportion of clinical genetics activities relating to the breast-ovarian cancer syndrome, counsellors are eager to have information relating to this specialty. However, in comparison to clinical activity, there is relatively little research being published about hereditary breast and ovarian cancer. The syndrome was the topic of 3.5% of the 2939 abstracts at this year's American Society of Human Genetics Meeting, and was the topic of 1.2% of 2104 articles published in the *American Journal of Human Genetics* over the past four years. We believe that research efforts should keep pace with the growing demand for cancer genetics services. In addition, clinical services will be optimised with the coordinated development of regional cancer genetic centres and subspecialisation of genetic counsellors. Given the high proportion of genetic counsellors who provide services predominantly in the area of hereditary cancer, it seems prudent that counselling programmes should offer specialised training programmes in this discipline.

Authors' affiliations

A Andermann, S A Narod, The Centre for Research in Women's Health, Sunnybrook and Women's College Health Sciences Centre, Toronto, Ontario, Canada

Correspondence to: Dr S Narod, The Centre for Research in Women's Health, 790 Bay Street, 7th Floor, Toronto, Ontario M5G 1N8, Canada; steven.narod@swchsc.on.ca

REFERENCES

1 **Zimmern R**. Genetics services: briefing encounters. *Health Serv J* 1999;**109**:24-5.
2 **Andermann A**. *Patient education, risk communication and informed choice: women with a family history of breast cancer who present to primary care.* DPhil (PhD) thesis, Oxford University, 2000.
3 **Statistics Canada Census Data**. Ottawa, Ontario: Statistics Canada, 2001 (http://www.statcan.ca).
4 **Wonderling D**, Hopwood P, Cull A, Douglas F, Watson M, Burn J, McPherson K. A descriptive study of UK cancer genetics services: an emerging clinical response to the new genetics. *Br J Cancer* 2001;**85**:166-70.
5 **Sobol H**, Bignon Y, Bonaiti C, Cuisenier J, Lasset C, Lortholary A, Nogues C, Stoppa-Lyonnet D, Eisinger F. Four years analysis of cancer genetic clinics activity in France from 1994 to 1997: a survey on 801 patients. *Dis Markers* 1999;**15**:15-29.
6 **Hodgson S**, Milner B, Brown I, Bevilacqua G, Chang-Claude J, Eccles D, Evans G, Gregory H, Moller P, Morrison P, Steel M, Stoppa-Lyonnet D, Vasen H, Haites N. Cancer genetics services in Europe. *Dis Markers* 1999;**15**:3-13.
7 **Farmer J**, Chittams J. Professional status survey 2000: national society of genetic counselors. *Perspect Genet Couns* 2000;**22**:S1-10.