Experiences of Genetic Counselors in Referring Young and Metastatic Breast Cancer Patients to Support Services: A Needs Assessment

Katherine E. Boninil[1*], Elizabeth Bourquardez Clark[2*], Robin H. Pugh Yi[3], Erica Kuhn[4], Jennifer R. Klemp[5], Diane Rose[6], Kelly N. Owens[6], Piri L. Welsh[6], Debra Duquette, MS, CGC[7], Susan J. Friedman[6], & Marleah Dean[2,8**]

[1]The Institute for Genomic Health, Icahn School of Medicine at Mount Sinai, New York, NY; [2]Department of Communication, University of South Florida, Tampa, FL; [3]Akeso Consulting, Vienna, VA; [4]Susan G. Komen, Dallas, TX; [5]Division of Clinical Oncology, Caris Life Sciences, Irving, TX ; [6]FORCE, Tampa, FL; [7]Feinberg School of Medicine, Northwestern University, Chicago, IL; [8]Health Outcomes & Behavior Program, Moffitt Cancer Center, Tampa, FL. *KEB and EC are co-first authors. **MD is the senior author.

BACKGROUND

- Young (≤45yo) and metastatic female breast cancer (yBC and mBC) patients often struggle to find credible information about support services that are critical for optimizing health outcomes.
- These populations meet national guidelines for genetic evaluation and are therefore likely to interact with a genetic counselor (GC).
- **Objective:** Explore GCs' experiences interacting with yBC and mBC patients and their familiarity, referral patterns, and perceived referral barriers in relation to support services, to inform the development of resources for the GC profession.

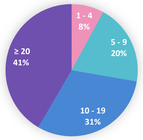
METHODS

- GCs who provided care to breast cancer patients were eligible.
- An online survey, using USF's Qualtrics platform, was distributed to FORCE healthcare subscribers and NSGC Cancer SIG members.
- **Support services** were defined as programs, services, or experts addressing relevant health issues/ topics for women with breast cancer (yBC and mBC).
- Respondents who answered less than 30% of questions or had suspected errors (conflicting data) across two or more questions were removed from analyses.
- SPSS and SAS were used to provide descriptive statistics and conduct analyses: frequencies for all closed-ended responses, displayed as valid percent; Mantel-Haenszel X^2 and Right-sided Fisher Exact Tests to test for statistically significant associations between select variables.
- This study was reviewed by the University of South Florida IRB and certified as exempt (Protocol 000339).

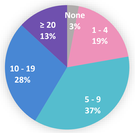
PARTICIPANTS (N = 117)

Role as genetic counselor[a]	
Work setting (N = 110)[b]	
Clinical setting	86%
Academic institution	25%
Community cancer center	16%
Tele-health company	13%
Nonprofit organization	10%
Private practice	3%
Industry	4%
Federally qualified health center	2%
Government agency	1%
VA hospital	0%
Professional society	1%
Years practicing (N = 89)	
Less than a year	9%
1-2 years	20%
3-5 years	21%
Over 5 years	50%

yBC Patients seen in the last 6 months (N = 117)



mBC Patients seen in the last 6 months (N = 116)



a. Respondents with missing data or errors have been removed from percentages.
b. Participants could select more than one option; total may not add to 100%.

RESULTS

As Years of Work Experience Increase, Familiarity with Specific Services Increases

Indicated Familiarity[a] with the Following Health Services / Topics:	Frequency Data by Years of Work Experience (N = 89) <1 %	1 - 2 %	3 - 5 %	>5 %	Statistical Data Analyses[b] Mantel-Haenszel X^2 p-value
Clinical Trials	4	9	15	37	**0.023**
Fatigue	0	1	2	12	**0.017**
Fertility Preservation	4	9	12	37	**0.022**
Long-term Health Issues[c]	0	4	9	20	**0.020**
Menopause Management	1	2	7	22	**0.005**
Palliative Care	1	4	8	24	**0.016**
Sexual Health or Intimacy	0	3	4	16	**0.036**

- Familiarity with the following support services/topics did <u>not</u> significantly increase with years of experience for:
  1) Breast Reconstruction, 2) Cancer Prevention,
  3) Communicating with Patients in Plain Language,
  4) Financial Issues, 5) Healthy Lifestyles, 6) Mental Health,
  7) Targeted Therapy, and 8) Tumor Biomarker Testing.

a. Respondents were asked if they were familiar with any guidelines, interventions, medical options, or resources available for women diagnosed with breast cancer, for the following topics/ services (in the table and the above note).
b. Those who did not indicate familiarity were used as the comparison group for each of the subgroups based on work experience.

Genetic Counselors' Familiarity with Specific Services Increases Their Frequency of Referrals for Certain Breast Cancer Patients

Referral Frequency (as # of Times) for yBC Patients During Last 6 Months (N = 114) Never %	1 %	2 - 4 %	5 - 9 %	≥10 %	Statistical Data Analyses[a] Mantel-Haenszel X^2 p-value	Indicated Familiarity[b] with the Following Health Services / Topics:	Statistical Data Analyses[a] Mantel-Haenszel X^2 p-value	Referral Frequency (as # of Times) for mBC Patients During Last 6 Months (N = 112) Never %	1 %	2 - 4 %	5 - 9 %	≥10 %
44	2	5	2	9	NS	Breast Reconstruction	NS	*53*	1	4	2	1
16	2	14	18	32	**0.001**	Cancer Prevention[c]	NS	*34*	7	12	10	11
35	1	11	4	4	**0.004**	Clinical Trials	NS	*42*	3	3	2	4
12	0	0	1	2	**0.004**	Fatigue	**0.004**	*11*	0	1	0	2
30	8	11	4	2	**0.016**	Fertility Preservation	NS	*44*	1	3	0	0
13	6	15	2	2	**0.019**	Financial Issues	NS	*16*	6	12	0	1
25	2	10	4	10	**0.017**	Healthy Lifestyles	NS	*29*	1	7	6	4
22	1	1	1	3	**0.010**	Longterm Health Issues[d]	NS	*19*	3	0	2	1
20	2	5	2	3	**0.002**	Menopause Management	NS	*25*	0	3	0	1
15	8	18	5	6	**0.017**	Mental Health	**0.005**	*18*	4	15	4	6
30	0	1	0	1	NS	Palliative Care	**0.002**	*26*	1	2	1	3
16	0	3	0	2	**0.002**	Sexual Health or Intimacy	**0.002**	*15*	2	1	1	2

a. Those who did not indicate familiarity were used as the comparison group for each of the subgroups based on work experience
b. For each of the following services, respondents were asked if they were familiar with any guidelines, interventions, medical options, or resources available for women diagnosed with breast cancer.
c. For mBC patient referral for cancer prevention services, there was a statistically significant association (p-value = 0.023) when those GC's who had never referred were compared to those who had ever referred (all other referral frequency groups combined; range: 1 time to > 10 times) using the right-sided Fisher's Exact Test (Pr > F).

Referral Patterns and Barriers for Services/ Experts/ Programs Addressing Needs of Breast Cancer Patients

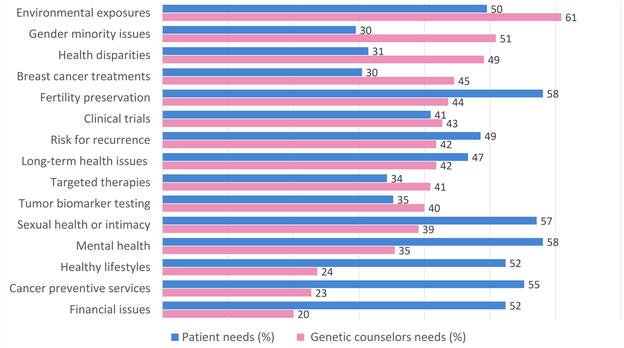
Services/ Experts/ Programs Addressing:	Excluded[a] %	Never Referred %	No Barriers %	Any Barrier %	Specific Barriers to Referral[b] Financial %	Patient Understanding of Value %	Lack of Local Programs/ Providers %	Language Barriers %	Medical Jargon or Health Literacy %
Cancer Prevention	25	18	21	37	51	56	30	16	37
Clinical Trials	25	53	5	17	15	70	40	5	55
Fertility Preservation	22	52	9	16	89	16	32	5	0
Genetic Testing	26	11	16	47	76	75	15	13	29
Healthy Lifestyles	28	44	15	14	13	69	38	19	6
Longterm Health Issues	23	68	5	3	0	75	50	0	25
Menopause Management	22	61	11	6	0	57	29	0	29
Mental Health	26	32	11	31	36	61	33	14	8
Palliative Care	22	70	4	3	0	100	0	25	50
Sexual Health	23	68	5	4	20	40	80	20	0

REFERRAL PATTERNS KEY		
75%	to	≤100%
50%	to	<75%
25%	to	<50%
0%	to	<25%

a. Responses with missing data or only one data integrity error were excluded; additionally, 17 respondents were excluded from all services due to > 2 data integrity errors across multiple questions.
b. Respondents could select up to 3 barriers for each service. The N for Any Barrier is used as the denominator for the percentages for each specific barrier.

EDUCATIONAL NEEDS

GC respondents selected topics related to breast cancer care & support that they felt warrant additional 1) continuing education opportunities for genetic counselors and 2) patient-facing educational materials. The top 15 are listed here.



CONCLUSIONS

- As years of work experience increase, GCs' familiarity with support services generally increases. For some services, familiarity was associated with increased frequency of referrals, particularly for yBC patients.
- Over half of participants reported that they never referred yBC or mBC patients to 6 out of 10 support services, suggesting that GCs may not perform this role at their institution or that there was a misinterpretation of that term.

PRACTICAL IMPLICATIONS

- Mentorship programs and CEU opportunities for GCs to help increase familiarity of support services and thus subsequent referrals.
- Providing patient-facing material may increase patient understanding of service value, mitigating the commonly reported barrier to support service uptake.
- Future research is needed to determine the role of GCs in making support service referrals (i.e., suggestions vs formal insurance referrals) and the most effective way to help yBC and mBC patients access them.

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