Evaluation of a Genetic Counseling Aid for Use in a Clinical Setting: A Pilot Study

Courtney Lewis[a,b], Jennifer Brzosowicz[a], Melissa Bugbee[a] , Patrice Fleming[a,b], Caitlin Stowe[a,b], Susan Friedman[c], Susan Vadaparampil[a,b], Tuya Pal[a,b]
H. Lee Moffitt Cancer Center , Risk Assessment Detection and Intervention[a], the University of South Florida, Department of Oncological Sciences[b], Facing Our Risk Empowered (FORCE)[c], Tampa FL

Background

•There is great variation in visual aids used during genetic counseling sessions for hereditary breast and ovarian cancer (HBOC). Furthermore, the acceptability of these aids has not been readily analyzed by patients seeking genetic counseling.

•Development of visually appealing health education material can make the material more appealing to high-risk individuals and may also enhance the individual's knowledge[1].

•A genetic counseling aid (GCA), in the form of a booklet, was developed as a study tool for patients at risk for hereditary breast and ovarian cancer (HBOC) for use during genetic counseling (GC) sessions.

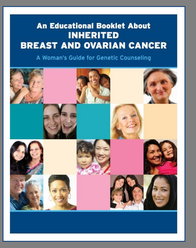
•The utility of the genetic counseling aid (GCA) was compared with printed
educational material (PEM), currently in use in the clinic.

Objective

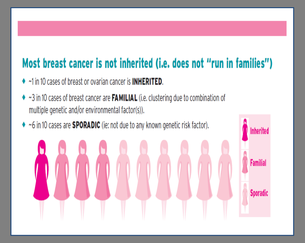
To compare the utility of the genetic counseling aid (GCA) and printed educational material (PEM) in the clinical setting

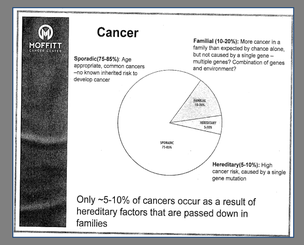
Study Tools

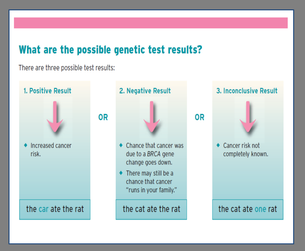
Genetic Counseling Aid (GCA)



Printed Educational Material (PEM)







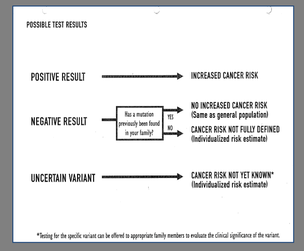
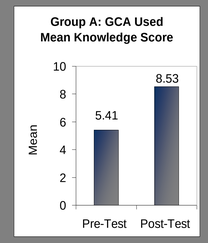


Table 1: Demographics

Demographic	Variable	Group A GCA Used	Group B PEM Used
Age		52.6 ± 12.6 (n=57)	49.6 ± 10.7 (n=46)
Ethnicity	White Black Asian American Indian, Aleutian or Eskimo	49 (83.1%) 8 (13.6%) 2 (3.4%) 0 (0%)	39 (86.7%) 5 (11.1%) 0 (0%) 1 (2.2%)
Martial Status	Single Married Cohabitating/Living Together Divorced Widowed	8 (13.6%) 39 (66.1%) 1 (1.7%) 7 (11.9%) 4 (6.8%)	8, 18.2% 28, 63.6% 1, 2.3% 6, 13.6% 1, 2.3%
Education Level	<High School High School Some College/Vocational School College Graduate Post-Graduate	3 (6.5%) 1 (2.2%) 10 (21.7%) 21 (45.7%) 11 (23.9%)	5 (12.5%) 1 (2.5%) 7 (17.5%) 23 (57.5%) 4 (10.0%)
Personal History of Cancer	Yes No	52 (89.7%) 6 (0.3%)	33 (73.3%) 12 (26.7%)
Family History of Cancer	Yes No	54 (93.1%) 4 (6.9%)	44 (97.8%) 1 (2.2%)

Table 2: Pre and Post Counseling Knowledge Scores

Question	Group A GCA Used (n=57)		Group B PEM Used (n=46)	
	Pre-Test Mean Knowledge Score	Post-Test Mean Knowledge Score	Pre-Test Mean Knowledge Score	Post-Test Mean Knowledge Score
One in 10 women has an altered breast cancer gene	.1034 ± .3072	.2105 ± .4113	.0435 ± .2062	.4348 ± .5012
One half of all breast cancer cases occur in women who have an altered breast cancer gene	.2542 ± .4392	.5536 ± .5016	.1522 ± .3632	.4348 ± .5012
A father can pass down an altered breast cancer gene to his children	.5254 ± .5036	.9298 ± .2577	.6522 ± .4815	.9783 ± .1474
The sister of a woman with an altered breast cancer gene has a 50% risk of having the altered gen	.5763 ± .4984	.8947 ± .3096	.4783 ± .5051	.8444 ± .3665
A woman who does not have an altered breast cancer gene can still get breast or ovarian cancer	.8814 ± .3262	.9825 ± .1325	.8043 ± .4011	.9348 ± .2496
Early-onset breast cancer is more likely due to an altered breast cancer gene than is late-onset breast cancer	.4310 ± .4996	.8421 ± .3679	.4348 ± .5012	.8222 ± .3867
A woman who has an altered breast cancer gene has a higher ovarian caner risk	.7647 ± .4291	.9898 ± .2577	.6522 ± .4815	.9130 ± 2849
All women who have an altered breast cancer gene get cancer	.7069 ± .4592	.8947 ± .3096	.5435 ± .5036	.9565 ± .2949
A woman who has her breasts removed can still get cancer	.6610 ± .4774	.7895 ± .4113	.5435 ± .5036	.8478 ± .3632
Ovarian cancer screening tests often do not detect cancer until it spreads	.3448 ± .4795	.7857 ± .4141	.3478 ± .4815	.6957 ± .4740
Having ovaries removed will definitely prevent ovarian cancer	.2203 ± .4180	.6667 ± .4756	.3043 ± .4652	.6957 ± .4652



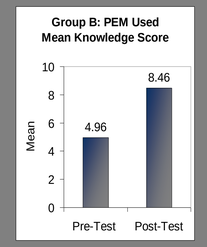


Table 3: Acceptability of Aids

Questions	Variable	Group A GCA Used (n=55)	Group B PEM Used (n=45)
How useful were the visual aids used in your genetic counseling session in helping you to unserstand cancer that runs in families?	Very Useful Useful Somewhat Useful Not at all Useful	39 (70.9%) 14 (25.5%) 2 (3.6%) 0 (0%)	33 (73.3%) 12 (26.7%) 0 (0%) 0 (0%)
Do you plan to use any resource materials given to you during your clinic visit again?	Yes No	53 (96.4%) 2 (3.6%)	45 (100%) 0 (0%)
Do you plan to share the materials with family members or friends?	Yes No	52 (96.4%) 2 (3.6%)	44 (97.8%) 1 (2.2%)
If yes, with whom?			
	Spouse/Partner	32 (58.2)	24 (53.3%)
	Sister	25 (45.5%)	21 (46.7%)
	Brother	12 (22.2%)	16 (35.6%)
	Daughter	30 (54.5%)	21 (46.7%)
	Son	14 (25.5%)	17 (37.8%)
	Friend	19 (34.5%)	17 (37.8%)
	Other	15 (27.3%)	15 (34.9%)

Methodology

• Study Eligibility:
Adult English-speaking female patients who presented for HBOC counseling.
Ability to provide written informed consent.

• Participants completed an 11-item standardized questionnaire developed by the National Center for Human Genome Research (NCHGR) Cancer Genetic Studies Consortium to measure knowledge of HBOC[2-5]. The questionnaire was completed:
1.) prior to their genetic counseling (GC) session (Timepoint 1) and
2.) following their initial GC session (Timepoint 2).
During Timepoint 2, patients completed 4 additional questions to measure the acceptability of the aid used.

• Patients were randomized into one of two groups according to the day of visit. Those who presented for genetic counseling on non-Wednesdays were counseled using the GCA (Group A). Those who presented on Wednesdays were counseled using the PEM (Group B).

Conclusions

•Knowledge scores were comparable between the group counseled with the PEM and the group counseled with the GCA.

•The majority of participants from both groups indicated that they planned to share the information they learned with the friends and/or family.

References

1. Michielutte, R., Bahnson, J., Dignan, M.B. & Schroeder, E.M. The use of illustrations and narrative text style to improve readability of a health education brochure. *J Cancer Educ* 7, 251-60 (1992).
2. Lerman, C. et al. The influence of psychological distress on use of genetic testing for cancer risk. *J Consult Clin Psychol* 65, 414-20 (1997).
3. Lerman, C. et al. BRCA1 testing in families with hereditary breast-ovarian cancer. A prospective study of patient decision making and outcomes. *Jama* 275, 1885-92 (1996).
4. Hopwood, P., Shenton, A., Lalloo, F., Evans, D.G. & Howell, A. Risk perception and cancer worry: an exploratory study of the impact of genetic risk counselling in women with a family history of breast cancer. *J Med Genet* 38, 139 (2001).
5. Lerman, C. et al. Controlled trial of pretest education approaches to enhance informed decision-making for BRCA1 gene testing. *J Natl Cancer Inst* 89, 148-57 (1997).