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Award Number: W81XWH-04-1-0562

TITLE: Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer

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REPORT DATE: June 2007

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
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REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
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1. REPORT DATE (DD-MM-YYYY) 01-06-2007		2. REPORT TYPE Annual		3. DATES COVERED (From - To) 17 May 2006 – 16 May 2007	
4. TITLE AND SUBTITLE Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-04-1-0562	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) James C. Coyne, Ph.D. E-Mail: jcoyne@mail.med.upenn.edu				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of Pennsylvania Philadelphia, PA 19104-6205				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results. They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance. The FORCE website (www.facingourrisk.org) serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project is intended to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It will identify the specific tasks with which they need assistance and the forms that competent coping takes. Results will give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer. To date, we have combined quantitative and qualitative analyses to identify and examine one of the most frequently discussed topics on the message boards; decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). Other papers in progress include the decision to undergo prophylactic mastectomy and subsequent decisions surrounding reconstruction, the lived experience of prophylactic mastectomy, and sense of self and renegotiation of identity following prophylactic mastectomy.					
15. SUBJECT TERMS Hereditary Breast Cancer, Internet Support, Qualitative Research, Consumer Collaboration					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
U	U	U	UU	60	19b. TELEPHONE NUMBER (include area code)

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Introduction

Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results. They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance.

Facing Our Risk of Cancer Empowered (FORCE) is a nonprofit organization and associated website (www.facingourrisk.org) devoted exclusively to the community of women at risk for HBOC. FORCE serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project involves evaluation of the activity and content of the FORCE website.

All data is collected online and is completely anonymous. The project samples message board discussions for emergent issues and themes, recurring problems, and strategies for successful coping. Procedures include formal content analysis of archived threads and specific queries posed to a representative consumer board of women participating in FORCE activities. Additional analyses focus on the social structure of the FORCE community, how it is used by members of HBOC families, and how it reflects the unmet needs with respect to the medical system.

This project is intended to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It will identify the specific tasks with which they need assistance and characterize forms of competent coping. Results will give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer.

Body

This project was approved for data collection on May 17, 2004. Since that time we have downloaded more than 8,600 separate threads appearing on the FORCE message boards between August 1999 and September 2004, formatted and categorized the resulting text documents for compatibility with our analytic software program, QSR-N-VIVO, and entered and coded significant portions of the data to facilitate searches and detailed analyses.

Key members of the research team attended training sessions to become proficient in N-VIVO data management and analyses. In addition, we were fortunate to be able to forge a collaboration with a senior qualitative sociologist who specializes in women's health and genetics—specifically issues related to HBOC. The combined efforts of our study investigators with expertise in qualitative and/or quantitative methodology facilitated detailed analyses of textual data with a degree of precision often lacking in purely qualitative research.

Initial quantitative analyses identified the themes of message board threads with the highest frequency and greatest continuity of activity. To date, we have combined quantitative and qualitative analyses to identify and examine the most frequently discussed topics on the message boards, which are as follows:

1) The first area of investigation is decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). Results of these analyses were presented at the *International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer* and were well received. A manuscript based on this presentation, entitled, *Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board* has been accepted for publication in the journal *Psycho-Oncology*. The article is enclosed in the appendices to this report. The abstract follows:

“The FORCE (Facing Our Risk of Cancer Empowered) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC). To understand the unique health concerns and emotional support needs of these women, we examined threads on the /FORCE/ archived message boards with relevance to the broader HBOC community. We report on a thread discussing the controversial decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. Twenty-nine women posted 177 messages over 7 months. Two main groups of women posted: 1) Women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life. 2) Women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. Frustrated by physicians’ lack of knowledge and contradictory media articles about the long-term consequences of HRT in BRCA+ women, they sought resources, emotional support and specific experiential knowledge from each other and generated a unique sense of community and a high level of trust.”

2) The second issue under investigation involves the decision to undergo prophylactic mastectomy (PM) and subsequent decisions concerning breast reconstruction. An oral presentation, *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*, was delivered at the 2006 *Society of Behavioral Medicine* annual meeting. The presentation discussed bilateral prophylactic mastectomy (BPM) as a preventive strategy available to women with BRCA mutations. Themes in the content of women’s communications on the FORCE message board were examined, to identify psychosocial and physical concerns surrounding the decision to undergo prophylactic mastectomy with or without reconstruction, the processes involved in such decision making, and the impact of their decisions on quality of life. Analyses of 203 messages were conducted using QSR N-Vivo, a qualitative software program. Findings suggest that women grieve during the decision process, feel confident in their choices, feel relieved after surgery, and feel empowered by the process of taking control of their bodies and future health.

3) The third issue under investigation is the lived experience of prophylactic mastectomy and related issues e.g., surveillance and reconstruction. Therefore, we are investigating the subject matter of these messages and the women’s purposes for writing about these issues with an emphasis on the subsequent socioemotional and practical details that went unaddressed in medical consultations leading up to the decision to undergo PM. We also are interested in learning more about how the women used the message board with these gaps in their preparedness, what sort of information and support they received from the message board and how they “gave back” to the message board regarding the issues surrounding prophylactic

mastectomy. Such reciprocity in social support seems to be an important theme in these messages. To conduct our research, we are analyzing threads about prophylactic mastectomies on the archived message boards during the period June 2000 – March 2004. We have finished a preliminary analysis involving the 7 women who made the most consistent contributions to the threads and are in the process of analyzing the postings of an additional 16. On the basis of the preliminary findings, we have begun writing a paper on the lived experience of decision-making these women go through, starting from the time they learned about HBOC and the possible morbidity and mortality associated with having a BRCA1/2 mutation. A working title for this article is: “The PM journey on the FORCE Website”. We will cover messages dealing with: influence of family history, genetic testing, pre-PM worries, pre-PM decisions, looking for help in making a decision, insurance coverage difficulties, deciding on surveillance instead of PM, day before PM thoughts and experiences, post-PM thoughts and experiences, trouble with implants, and giving information, opinions and advice. This manuscript should be ready for submission in Fall 2007 and is intended to lay the groundwork for more patient-oriented content in the medical consultations leading up to prophylactic surgery.

4) Another topic we are investigating is the psycho-social interpretation of problems women face post-PM with or without reconstruction, based on the works of Goffman and Charmaz regarding risks of disclosure, possible social stigma or rejection, sense of self and renegotiation of identity. This work, *Women with BRCA1 or BRCA2 mutations renegotiating a post-prophylactic*

mastectomy identity: Self-image and self-disclosure, based on a subsample of 21 women posting on the message board over a four-year period, was submitted once to the *Journal of Genetic Counseling* where it met favorable reviews and is currently being revised for resubmission. The abstract for this manuscript follows:

“The FORCE (Facing Our Risk of Cancer Empowered) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC). One of the most frequently discussed topics on the archived message board has been prophylactic mastectomy (PM) for women with a BRCA1/2 mutation. We reviewed the messages, over a 4 year period, of 21 high risk women and their “conversational” partners who originally posted on a thread about genetic testing, genetic counseling and family history. We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. The women sought emotional support, specific experiential knowledge and information from each other. They frequently found revealing their post PM status problematic because of possible negative reactions and adopted self-protective strategies of evasion and concealment outside of their web-based community. The FORCE message board was considered to be a safe place in which the women could be truthful about their choices and feelings. Results are discussed in terms of Goffman’s concepts “stigma” and “disclosure” and Charmaz’s concepts “interruptions,” “intrusions” and a “dreaded future”.”

5) The fifth issue we have begun to investigate concerns the attributions made about their cognitive and affective experiences following prophylactic oophorectomy (PO). Understanding attributions for changes is important, as these influence satisfaction with decisions to undergo PO as well decisions about symptom management. Liisa Hantsoo, a junior member of our team, presented data examining attributions of cognitive and affective changes among women who had undergone PO at the 2007 *Society of Behavioral Medicine* conference in a presentation entitled,

Women's Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy. Results indicated that women posted about as often concerning positive mood and cognition changes as negative changes, but were more likely to attribute changes to hormonal rather than nonhormonal causes. While women were about equally likely to attribute positive or negative changes to hormonal effects, negative experiences were more often attributed to loss of hormones than were positive experiences. These data suggest that women who experience negative changes following PO may consider utilizing contraindicated hormone replacement to obtain more positive outcomes. These data are currently being prepared in manuscript form.

Additionally, a poster summarizing the goals of the grant and its progress was presented at the June 2005 Department of Defense Era of Hope conference. Dr. Regina Kenen also gave an invited talk entitled "FORCE as a Web Based Support Group and Information Source" to a Hereditary Breast/Ovarian Cancer Family support group at the Royal Marsden NHS Trust, October, 2005.

Findings to date suggest that women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community. These women face potentially life altering decisions concerning risk management strategies and struggle to balance risk reduction and quality of life.

The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. They experienced feelings of loss, as well as a changing sense of themselves as women during the adjustment to risk reducing prophylactic surgeries, and repeatedly expressed concern over the inadequacy of current research to address the issues most relevant to their health and quality of life. Specifically, studies that report the effects of HRT on menopausal women tend to focus on natural or surgical menopause in older women, but do not include younger high-risk women who have undergone surgical menopause for reduction of breast cancer risk. Nor do such studies explore the effects of alternate forms of HRT, including individualized bio-identical formulations. Controlled studies examining the impact of multiple forms of HRT on breast cancer risk in BRCA+ women following PO are warranted. Overall, there are substantial gaps in the preparation of these women for the experiences associated with decision making concerning risk management and the consequences of these decisions. Our goal is to produce results that both improve their preparation and strengthen subsequent support processes, particularly among women who do not have the benefit of the unique resources of F.O.R.C.E.

Key Research Accomplishments

- Assembled investigator team
- Hired and trained research assistants
- Key personnel attended QSR-N-VIVO training
- Downloaded and converted entire FORCE archives HTML files to RTF format for use with QSR-N-VIVO, resulting in 5000 pages of searchable text documents
- Created a taxonomy of key issues warranting investigation based on frequency, volume, and duration of threads on the message boards
- Assembled FORCE consumer board for formal review and discussion of findings (member checking)

- Completed analyses of first topic: Decisions surrounding the use of HRT following PO
- Presented early results at the *International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer*
- First manuscript, *Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board*, has been accepted in *Psycho-Oncology*.
- Analyses of second topic in progress: “Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board.” Decision to undergo prophylactic mastectomy with or without reconstruction, the processes involved in such decisionmaking, and the impact of decisions on quality of life. Initial results were presented at the 2006 *Society of Behavioral Medicine* annual meeting.
- Analyses of third topic in progress: “The PM journey on the FORCE Website.” Prophylactic mastectomy and related issues, e.g., surveillance and reconstruction, influence of family history, genetic testing, pre-PM worries, pre-PM decisions, looking for help in making a decision, insurance coverage difficulties, deciding on surveillance instead of PM, day before PM thoughts and experiences, post-PM thoughts and experiences, trouble with implants, and giving information.
- Analyses of fourth topic in progress: Psycho-social interpretation of problems women face post-PM regarding risks of disclosure, possible stigma or rejection, sense of self and renegotiation of identity.
- Manuscript entitled, *Women with BRCA1 or BRCA2 mutations renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure*, was submitted once to the *Journal of Genetic Counseling* and is currently undergoing revision for resubmission.
- Presented results of analysis describing attributions of affective and cognitive changes following PO at *Society of Behavioral Medicine*.

Reportable Outcomes

Completed Presentations:

Coyne, J.C., (September, 2005). *So genetic testing is not traumatic, now what?* Invited Lecture: Grand rounds, Department of Medical Genetics, University of St. Andrews School of Medicine.

Hantsoo, L.V., Coyne, J.C., Friedman, S., & Palmer, S.C. (2007). *Women’s Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy*. Poster presented at the Society of Behavioral Medicine Annual Meeting, Washington D.C.

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (in press) Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. *Psycho-oncology*.

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (June, 2005). *Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board*. Paper presented at the 9th

International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer, Philadelphia.

Kenen, R. H. *FORCE as a Web Based Support Group and Information Source*. Presented at Hereditary Breast/Ovarian Cancer Family support group at the Royal Marsden NHS Trust, October, 2005.

Palmer, S. C, Shapiro, P. J., Friedman, S., Coyne, J. C. (June 2005). *Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer*. Poster presented at the Department of Defense Era of Hope Conference, Philadelphia.

Shapiro, P. J., Kenen, R. H., Hantsoo, L., & Coyne, J.C. (2005). *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*. Paper presented at the 2006 Society of Behavioral Medicine Annual Meeting.

Work in Preparation or Under Review

Kenen, R.H., Shapiro, P.J., Hantsoo, L., Friedman, S., & Coyne, J.C. *Women with BRCA1 or BRCA2 mutations renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure*. Under revision for Journal of Genetic Counseling.

Kenen, R.H., Shapiro, P.J., Hantsoo, L., Friedman, S., & Coyne, J.C. *Seeking Answers, Making Choices: Three Case Studies of BRCA1/2 Women Posting on a Support Group Message Board*.

Conclusions

This project is a unique collaboration between a multidisciplinary team of researchers and a non-profit organization of consumers that serves the needs of women and families affected by HBOC. Progress to date includes identification of key issues that affect both the immediate and long-term health and quality of life of women at genetic risk for breast and ovarian cancers. Detailed analyses integrating high-risk women's perspectives on these issues with the relevant medical and psychosocial literature are underway, with the first topic completed and three additional topics near completion. In addition, we have identified a number of topics for future analyses, including exploration of 1) women's psychosocial and pragmatic support needs during significant events such as receipt of genetic test results, cancer diagnosis, and cancer recurrence, 2) unmet healthcare needs, 3) and satisfaction with physician care.

General findings suggest that women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community as a means of coping with potentially life altering decisions concerning risk management. The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. In their struggle to balance risk reduction and quality of life, they repeatedly expressed frustration with the inadequacy of current research to address these issues. In addition to their individual concerns, women expressed concern for their children and future generations. This project gives voice to

their concerns—a collective voice in their own words with the potential to shape future clinical, public policy, and research agendas for women and their families who live with inherited risk of cancer.

References

None

Appendices

1. Published Manuscripts

APPENDIX: 2007 PUBLISHED JOURNAL ARTICLES, PRESENTATIONS

JOURNAL ARTICLES PUBLISHED:

Kenen, R.H., Shapiro, P.J., Friedman, S., Coyne, J.C. Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board. *Psychooncology*. 2007 Jan 17; [Epub ahead of print]

JOURNAL ARTICLES UNDER REVIEW:

Kenen, R.H., Shapiro, P.J., Hantsoo, L., Friedman, S., Coyne, J.C. Women with BRCA1 or BRCA2 mutations renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure. Submitted to *Journal of Genetic Counseling*.

POSTERS:

Hantsoo, L., Coyne, J.C., Friedman, S., Palmer, S.C. Women's Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy. Presented at Society of Behavioral Medicine Annual Meeting, March 2007, Washington D.C.

WORK IN PREPARATION:

Seeking Answers, Making Choices: Three Case Studies of BRCA1/2 Women Posting on a Support Group Message Board.

Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board

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Abstract

The Facing Our Risk of Cancer Empowered (FORCE) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC). To understand the unique health concerns and emotional support needs of these women, we examined threads on the FORCE archived message boards with relevance to the broader HBOC community. We report on a thread discussing the controversial decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. Twenty-nine women posted 177 messages over 7 months. Two main groups of women posted: (1) Women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life. (2) Women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. Frustrated by physicians' lack of knowledge and contradictory media articles about the long-term consequences of HRT in BRCA+ women, they sought resources, emotional support and specific experiential knowledge from each other and generated a unique sense of community and a high level of trust. Copyright © 2007 John Wiley & Sons, Ltd.

Keywords: internet; prophylactic surgery; BRCA; hereditary risk of cancer; quality of life

Received: 14 March 2006
Revised: 28 November 2006
Accepted: 9 December 2006

Introduction

Approximately 5–10% of the estimated 213 000 women who will be diagnosed with breast cancer and the 20 000 who will be diagnosed with ovarian cancer in 2006 [1] will have an identifiable genetic mutation predisposing them to hereditary breast and ovarian cancers (HBOC). For women carrying a BRCA1/2 mutation, the lifetime risk of breast cancer is approximately 50–85% and the risk of ovarian cancer is approximately 15–40% [2,3]. Although there are a number of strategies for managing HBOC risk, including surveillance, chemoprevention, and prophylactic surgeries [1,4], each can have negative consequences for both immediate and long-term health and quality of life. Thus, women seeking to reduce their cancer risk face complex medical decisions. Emerging data describing the risk-reduction benefits of various measures can provide a basis for decision-making [5–9]. Unfortunately, many women in the community do not have access to specialized genetic services where such information can be individual-

ized and discussed in educational and counseling sessions. For these women, the internet can provide a lifeline to support and information.

Although there are a number of internet sites for women with breast or ovarian cancer, *Facing Our Risk of Cancer Empowered* (FORCE) is the only website exclusively serving the needs of women at high-risk for HBOC. FORCE receives approximately 1 000 000 hits per month from all over the world and has been described as the best site in the world for HBOC patients to be directed by their physicians [10]. The website provides links to informational resources, a 24 hour message board, and a chat-group. Since FORCE was started in 1999, more than 50 000 messages have been posted. The archives include posts covering a wide range of HBOC related issues from the initial decisions to undergo genetic testing to discussions of the long-term physical and quality of life consequences of various risk management and preventive strategies.

As participation on the FORCE message board likely reflects unmet needs, the limitations of community resources, and the ambiguity

surrounding appropriate medical care for high-risk women, these posts provide a unique opportunity to examine the difficulties high-risk women face as they strive to reduce their cancer risk and regain control over their lives. As part of an ongoing project to identify and understand the needs of the high-risk community, we examined emergent themes in the content of women's communications on the FORCE message boards and identified several concrete problematic situations. One of the most prominent issues centered on the decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO).

Many women with BRCA mutations choose prophylactic surgeries—removal of both breasts and/or removal of the ovaries because these procedures are associated with the greatest risk reduction [11,12]. PO confers up to a 50% reduction in risk for breast cancer and up to a 95% reduction in risk for ovarian cancer among BRCA positive women [7,9]. However, these risk reduction benefits are not without cost and the physical and emotional sequelae of PO, particularly for younger women, can be substantial [13]. Surgically induced menopause hastens many of the changes associated with gradual aging including vaginal atrophy, reduced libido, accelerated bone loss, and increased LDL cholesterol [14,15]. To complicate matters, HRT traditionally used to reduce the negative impact of early menopause may be contraindicated in women with BRCA mutations. Research on the use of HRT in mutation carriers is in its early stages and the medical community cannot provide definitive evidence about the possible value or harm of HRT for this population.

Faced with life altering decisions in an atmosphere of medical uncertainty, the women in the FORCE high-risk community turn to each other for information and support. In this paper, we focus on their psychosocial and physical concerns surrounding the choice of PO for risk-reduction and the processes involved in the decision to use HRT for management of menopausal symptoms and related health issues.

Method

Selection of thread

This study was approved by the University of Pennsylvania School of Medicine. In order to protect the privacy of women currently posting on the FORCE message boards, only the message board archives were examined. These archives are password protected and access is provided by the executive director on a case by case basis. We used the quantity of messages and duration of the ongoing conversation to identify threads with

significant interest to the FORCE community. The thread titled, *Impacts of Surgical Menopause and Hormone Replacement Therapy Usage (PO-HRT)* was the most active of all individual threads, consisting of 177 messages posted in a continuing conversation over a 7 month period during 2001–2002. In addition, text searches of the entire archive were performed for posts including key words hormone replacement, estrogen replacement, HRT, and ERT. An additional 708 noncontiguous posts dealing with the same issue appeared throughout the 5 years of archived posts, but these did not occur in the concentration and duration of the selected thread. Thorough reading of these related posts insured that the selected thread was representative of the shared concerns, uncertainty, and support surrounding the issue of HRT following PO on the FORCE message boards, and allowed examination of the issues over time within the context of emerging medical literature.

Participants

Twenty-nine women contributed to this thread between August 2001 and February 2002. We do not have data concerning 'lurkers' or visitors to the website who may have viewed the thread without posting. For the purposes of this report, the screen names of individual posters were replaced by pseudonyms to assure anonymity.

Analyses

Analyses were conducted in several stages using a mixed method design combining quantitative and qualitative approaches and both inductive and deductive reasoning. Applying a similar process to that used in developing a semi-structured interview guide or moderator's focus group guide, broad topics of interest were first identified by review of the existing literature and informed by our experiences working with the high-risk population. Specifically, the areas of communal problem-solving, medical uncertainty, value or perspective discrepancy with professionals, and processes of social and emotional peer-support were selected as themes for investigation. Quantitative analyses involved counting women who posted at various times and in various categories, and the number and content of posts dealing with specific themes.

To ensure the integrity of the qualitative aspect of this study, a qualitative sociologist who was not involved in the genesis of this project and initial identification of themes analyzed the HRT and oophorectomy thread using an inductive process involving coding and identification of recurring patterns, relationships and processes in the data, emphasizing the participants' own accounts of their phenomenological and social world [16–18]. A conceptual account based on the women's postings

on the message board was developed, emphasizing the meaning in human action, and helping to identify various elements in the thread under investigation which might otherwise remain hidden [19]. To ensure that all major themes were identified, we used close reading and hand coding of the data as well as parallel coding by a second investigator using N*Vivo by QSR software, a qualitative analysis software program.

We then examined posts for evidence of *a priori* themes, integrated these with new themes derived from the posts, and then revised our initial tentative ideas about these issues in light of the content revealed by qualitative analyses. Posts were reexamined in an iterative fashion, adding explanatory detail and support for both revised *a priori* themes and the themes generated by the qualitative analysis. The latter dealt primarily with the women's use of the new social space provided by the FORCE internet support group, and the processes of developing trust and social community [20].

Results

Poster characteristics

Of the 29 women participating in this thread, 17 posted more than three messages; five posted 10 or more messages, nine women only posted once, and one woman dominated with almost one quarter of the messages posted under three screen names. Two main groups of women posted: (1) women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life, and (2) women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. The majority of women were in their 30s; some were breast cancer survivors and others were *previvors*—survivors of a predisposition to breast and ovarian cancers.

Content and themes

Overview

This thread represented a nexus of uncertainties that required near-term decisions with long-term consequences in an area marked by lack of consensus among physicians. The participating women were generally young, felt alone and vulnerable, and wanted to gain some control over their lives. Frustrated by physicians' lack of knowledge about the long-term consequences of HRT in BRCA+ women and the contradictory information presented in media articles, they sought resources, emotional support and specific experiential knowledge from each other. These

women were concerned about the increased breast cancer risk associated with HRT, that they might essentially be undoing the benefits derived from PO by taking HRT, and that the immediate and long-term quality of their lives would be compromised without it.

While the provision of emotional support was a key element, the women were also eager to learn the latest scientific and medical data. Many of the posts cited information from recent pertinent articles in high prestige professional journals accompanied by informed critiques which generated further discussion. They also shared contact information for various medical centers around the country, provided telephone numbers for diverse organizations such as the National Women's Institute and The Women's International Pharmacy, and directed women to other websites that provided relevant information.

Building a social community; reducing a sense of isolation

The FORCE community consists of women in a similar predicament whose common breast/ovarian cancer risk outweighs their differences. Outside of members of their families, they did not meet many women who were BRCA+ in their every day life. Even though some of the women reported being surrounded by supportive relatives, friends and doctors, they still felt alone at times and wanted to reach out to someone who really understood them.

We may have great doctors, we may have supportive friends and family members—but unless those folks have experienced breast or ovarian cancer, they can't understand what we have gone through, what we face, and what we fear. That is why FORCE is so important. . . it allows us to share with other women who really understand. You are not alone in this. Take care! Hugs, Francine
I really appreciate all of you being out there. My husband is still a little in denial and doesn't really proactively talk about this situation. I'm a little in denial too, so I can't blame him, but oh, do I feel lonely and alone in this sometimes. Deidre

The messages on this thread included several different substantive topics, asked and answered questions, spoke of tears and anguish, but these were mixed with words of optimism and humor. Humor was a hallmark of this thread. It lifted the women's spirits and provided a source of bonding.

Edith, Nora & Tessa- Thanks for all of the wonderful giggles. Nora, were you tickling my spirit on your walk? I couldn't stop giggling for some reason and I have a feeling you were behind it. Okay. . .let me ask you all a couple of questions. HRT makes one lose weight? *looks for silver lining* Also, how is your sex drive? That isn't a proposition. . . I'm interested for myself. . .and DH. Tessa. . .I bet you are gorgeous bald! Have you thought about keeping it shaved? I kept my head shaved a half year after chemo and loved it. Candi

Beyond its role in providing social and emotional support for women who felt isolated, the FORCE community also played another pivotal role. It functioned as a source of information and a means for communal problem solving. The following message by Erin concisely represents many of the themes in this thread. Erin raises the two crucial issues that the women posting on the thread are concerned about, PO and the use of HRT. She wants to learn what another oncologist treating BRCA+ women says about it. Here she is gathering medical information, but is also asking about personal experiences. In one paragraph, she welcomes a poster back and reaffirms her importance to the group. She does not use 'I' when talking about missing her, but 'we' indicating that she feels connected to and able to speak for others. She signs the posting 'your HRT sister' which highlights the fictive kin (nonaffinal or blood relations that are considered part of the family) aspect of the thread.

Dear Nora, It's great to have you back!! We missed you! I know this issue of HRT is so complex. Here we are doing the pm/ooph trying to save our lives, but then we still need to make this really important decision to take or not to take HRT. I will be really interested to hear what your oncologist has to say tomorrow. Are you currently having any side affects from not taking HRT? your HRT sister, Erin

Deidre's post is also typical of many of the messages. She shifts back and forth between her quest for information and her personal feelings and opinions. She is at the beginning of her decision-making journey considering the future consequences of her choice of PO as a risk reduction strategy.

I believe I will have the ooph this year. I've become extremely paranoid that my cells are becoming cancerous as I speak. Where did you get informed about the post-op effect, HRT, hists, etc.? I feel like I really need this doctor to spend a long time explaining everything, but I know most give you the rush after about 15 minutes. Why do most of you have an ooph AND a hist, not to mention the PM? I always thought the detection for breast was so good that I'd catch it and cure it if it happened. Also heard that the ooph lowers risk of bc. Deidre

Sharing a dilemma; making a choice

The search for an HRT regime that would not increase their breast/ovarian cancer risk was fueled by women who were dissatisfied with how they felt and looked. Reduced energy level, a certain mental 'fuzziness', lack of libido, changes in skin, and weight gain were the most prevalent unwelcome changes mentioned in their messages. Their angst may be due in part to their young age, as most of these women were in their 30s or early 40s, or had undergone PO while in that age range. As a consequence, reactions to their abrupt surgical

menopause may be stronger and symptoms perceived more negatively than those of older women who experience the more gradual changes associated with natural menopause. Nora's complaints about the negative side effects of her PO without HRT were typical.

I'm two years' post TAH/BSO [total abdominal hysterectomy with bilateral removal of fallopian tubes and ovaries] and am dissatisfied with the dramatic changes to my energy level, memory, libido, skin, and weight. This dissatisfaction stems directly from the surgical-menopause....I'm going to take HRT (a minuscule amount that is as close as possible to the natural versions: 'individualized bio-identical hormone replacement'. My strongly opposed, otherwise highly supportive physicians, don't know this yet. And, it was actually another reason for my second breast removal—to allow for that additional slight edge of HRT. Sick but true. Nora

While Nora made her choices after a great deal of thoughtful investigation, she like many of the women posting on this thread, expressed distress about the loss of their fertility and how PO affected their entire bodies. Nora writes poignantly about mourning both the loss of her breasts and her fertility. She is upset that others have downplayed the 'invisible' loss of her ovaries—the primary sex characteristic responsible for feminization of the body, reproduction, and hormonal regulation—but empathized with the loss of her breasts, which are less crucial to the essence of being a woman. Her experiences with both friends and physicians suggest that external appearance, indeed conformity to societal norms of what features define the female body, supersedes what is necessary for her health and well-being.

you can't 'see' reproductive organs but the whole world can 'see' boobs...With both medical people and friends there's been almost nonchalance about my TAH/BSO and so much fuss about the loss of my breasts... Don't get me wrong in that I really miss mine. Perhaps I'm still perturbed with a general societal value that was placed on my breasts instead of my unborns. Perhaps I'm not done mourning the latter. Nora

These women were attempting to deal with the aftermath of their POs and represented approximately half of those posting on this thread. The remaining women were still considering this option. Some had scheduled their surgery, but were afraid of both the physical and emotional after effects. They had heard all sorts of stories and wanted to learn about other women's experiences to get a 'reality check'. Reading about the unpleasant side effects upset some of the women who were contemplating PO.

Diane wrote about how frightened she was of the unknown. She worried that an oophorectomy would affect her personality, leaving her with the 'flatness' others described, and how that would

affect her marriage. She was concerned primarily with the existential question of who she was now and who she might become.

Is it just me or does everything I hear sounds worse and worse for the ooph? I am just so scared of the unknown of how I will be after. I am known for my passion. When I feel passionate about something, watch out. To hear that I might not be this way after is pretty scary. How do you cope with all of this? How am I going to go in and do this knowing my personality might be different.... Sorry to be thinking out loud but if I will be a different person, will it be worth it? Diane

Others felt overwhelmed by the enormity of the decision they faced. Although Candi had hoped the discussion would clarify her options and simplify decision making, this thread served to highlight the complexity of the issues and evoked the sense that it was a *no win* situation.

okay... It's been an hour since I've read this string and I'm still crying. I HATE MAKING THE CHOICE BETWEEN TWO EVILS!!!! I agree with EVERYONE and am ripped apart. I have to do everything I can to live as long as possible for my daughter, husband, and myself. Yet I know all of the problems I have had with my many surgeries and KNOW that I will be terribly messed up with no guarantee they will figure out the right combo of drugs for me to fix the 'side effects.' I hate that I have to live this way. Candi

These women apparently felt safe enough on the FORCE message board to express their deepest emotions whether they dealt with fear of the unknown, worry about changes in their personalities, being distraught about having to choose between 'two evils' or mourning the loss of their female body parts. Not only did they feel compelled to make decisions they believed no woman should have to make, but to compound their distress, they lived in a society that placed a very high premium on breasts while undervaluing the severe physical and psychological implications of a PO.

Medical uncertainty and value discrepancy

In 2001–2002, during the seven month period when this thread was active, physicians could not agree on whether women who were BRCA+ and opted for a PO should use HRT [21,22]. The available clinical epidemiological data from older and non-BRCA+ women was of limited relevance, and offered little in the way of guidance for decisions about HRT. This was reflected in the conversations the women reported having with their doctors and in reaction to their searches for a definitive medical answer. Most of the women, though not all, were posting on this thread because they wanted to begin receiving some form of HRT.

This is one area that I am trying to decide about too. My breast surgeon says 'no' and gyn says 'yes' to HRT

(Haven't had my surgeries yet, am planning for early January, so I have some time to research this HRT dilemma) Would also love to hear from the group on this subject too. Erin

I wish there were specialists in this area of knowledge. Right now, it seems to be such an unknown factor as to what to do! Clear as mud! Darlene

There also seemed to be a discrepancy between the values of the physicians and the values of some of the women.

My doc is very cavalier about the emotional side of this, says I don't need testosterone because libido is 'all in one's head,' but I may decide he's wrong if I become emotionally numb. Deidre

According to their messages, some of the women's doctors, particularly their oncologists, did not want them to take HRT until more research had been conducted. The women reported their sense that their oncologists were more interested in keeping them alive than they were concerned about the quality of their lives. The women, however, were interested in both quality and quantity of life.

Here again is where things are soooooo confusing. My oncologists don't want me on anything that even closely resembles estrogen. They don't want me on testosterone as a breast cancer survivor (different situation from all you pre-vivors out there). I was told that there aren't any conclusive studies on safety in bc survivors (again, not talking about bc pre-vivors) Tina

I know oncologists are against hormones. However, sometimes I feel they may be more interested in survival than in quality of life. I wish there were more definitive answers out there. It seems horribly cruel to deprive us of hormones that keep 'normal' women healthy. They need to figure out why estrogen becomes the enemy of some! Darlene

Trust your body; trust yourself

Throughout the message boards, posts appeared emphasizing that every woman was unique and that any decision was 'right', if it was right for that individual. These posts, along with those presenting individualistic experiential perspectives on surgical menopause and HRT, provided an ambience of acceptance and safety, allowing women to be more open about their feelings and share very personal experiences, even when these did not fit the general pattern. This freedom to be 'oneself' also fostered the development of a social community.

The post by 'Anonymous,' illustrates this with a large dollop of humor. She reminds the women that their own menopause experiences will not necessarily conform to the models they have read about in the media or research literature. Her message echoes the theme 'trust your body, trust yourself'.

Dear all, My two cents... As a long time sufferer of hormone hell (pre-menopause) I totally, totally get the subtleties that hormonal differences can create... When hormones go awry the way you feel things can feel blunted... I always likened it to what I imagined wearing a condom felt like... except it was lining my insides and not my outsides. That being said, I can tell you that it's been 1.5 years since chemo fried my ovaries and 6 months since those little falafel balls were taken out. I actually feel better than I did for much of my 'healthy' years... you shouldn't have any preconceived notions about what life without HRT is... I think we get wrapped up in what our research and the media tells us it should be. All of your reactions and symptoms are valid, but they are personal to you. Over and out. Anonymous

Edith, who had suffered from what sounds like premenstrual syndrome (PMS) most of her adult life, sends a similar message challenging the universality of post oophorectomy difficulties. She exults in her post-oophorectomy existence and writes about how much better she looks and feels taking HRT than she did before. She answers a message from a distraught poster, providing comfort along with the specifics of her HRT use.

Dear Candi, I have never looked or felt better in my life since my ooph and pm... I am MADLY IN LOVE with not having a period, and figure I get one week per month minimally of not being achy, weeping, greasy, ugly and a general mess. I am on natural hormone crèmes compounded by a lab and prescribed by an internist. My ca123 and ca27/29 are VERY LOW and my estrogen level is on the low side of normal. I am also thinner and have a flatter tummy than at any other time in my life. Soooooooooooooooooooooo, so much for all the post ooph difficulties. They are not universal, so try not to despair too much. Happy Holidays, Edith

In sharing detailed experiential information about the outcomes of their personal HRT decisions, posters like Anonymous and Edith empower women who are still in early stages of decision making to explore individualized options to achieve personal well-being. In the following quote, Trixie thanks Edith for previous useful advice; in essence, each woman was passing the torch by sharing the details of her own successful natural HRT regimen to others.

Edith and others, I have been struggling with the hormone issue since my hyst/ooph [hysterectomy/oophorectomy] a year ago. I had decided on ERT [Estrogen Replacement Therapy]... But, I hadn't been able to get it right—and was working with a dr. that thought I was an equation. Edith had advised me to check out the natural hormone months and months ago... I am now on natural progesterone, natural estrogen (triest), and a little testosterone, and feeling much better. I haven't spoken to the dr yet about it, but, the books seem to suggest that I can wean off the estrogen over the next few months, stay on the progesterone, and probably still feel good... A belated thanks to Edith. Best regards, Trixie

Continuing PO/HRT Discussion on archived message board

Collective wisdom and reciprocity

Within six weeks of the final post on the *Impacts of Surgical Menopause and Hormone Replacement Therapy Usage* (PO-HRT) thread, the topic surfaced again and then appeared periodically in the archives until 2004. Both the quantity and duration of these subsequent threads were considerably less than the PO-HRT thread, with threads lasting between 1 and 9 days with a maximum of 30 posts. Fourteen of the original 29 women who participated in the PO-HRT thread posted on the topic during this period to share the information they had gathered previously, describe their experiences with PO and HRT, and offer support. They were reciprocating what FORCE sisters had given to them when they needed guidance and encouragement. Rather than reiterate the content of the PO-HRT thread, links to the archived thread were provided so that readers might view the content in its entirety. In this way, the thread became part of the collective wisdom of the FORCE sisterhood—a casebook of concerns, symptoms, and solutions occurring under conditions of medical uncertainty.

More information; more confusion

In July of 2002, approximately 5 months after the PO-HRT thread ended, a press release was posted on the FORCE message board announcing that the estrogen plus progestin arm of the Women's Health Initiative (WHI) clinical trials was closed due to the increased risk of invasive breast cancer, coronary heart disease, stroke, and pulmonary embolism in women taking estrogen plus progestin compared to those taking placebo. Three women involved in the PO-HRT thread participated in this thread, reiterating their concerns about QOL versus long-term health, and pondering the relevance of this information to their unique situations.

Kriz expressed anger and frustration at the news, aptly summing up the current limitations of medical knowledge and the difficulties that remain ahead for high-risk women facing decisions about PO and HRT.

I went a year with no HRT post ooph and watched my bone density go down and my cholesterol go up, my libido go away, my hair thin and so on. Now, after being on HRT for a year or so, I get to worry about cardiovascular disease and strokes and blood clots... And, I'm really wondering if there's a difference between medroxyprogesterone acetate and natural micronized progesterone (Prometrium) as I'm taking the micronized progesterone. But how long will it take for any studies on that to be done and reported on? Hmmmph!... Anyway, not sure what the point to my post is - maybe that I'm angry and I just need to vent! It's been said so many times before - there just are no easy answers regarding this.

Discussion

The objectives of this study were threefold; first, to discover and present high-risk women's psychosocial and physical concerns regarding surgically induced menopause; second, to clarify the processes involved in the decision to use or not use HRT, and third, to understand how the women use and benefit from an internet support group message board.

The specific findings need to be interpreted within the larger context of how individuals perceive risk and handle uncertainty—a complex and subjective process [23]. Women from HBOC families face a plethora of uncertainties—the uncertainty as to whether, or when, they will develop breast or ovarian cancer, as well as uncertainty surrounding the efficacy and risks associated with options. The main focus of the PO and HRT thread was the attempt by these women to take optimal steps toward reducing their high-risk for developing breast and/or ovarian cancer while minimizing the negative side-effects of their risk reduction strategy. Their concerns centered on the specific physical and emotional changes associated with menopause, particularly the immediate symptom distress following PO, but also the long-term impact of early menopause on physical health and quality of life.

Living with a high-risk of developing a life-threatening condition involves not only uncertainty but a considerable diminution of control over one's life—a highly esteemed value in western societies [24]. The women try to regain this control and resolve the decisional conflict they face by evaluating their options in terms of gain or loss. Resolution involves processing large amounts of new and difficult information and the message board serves as both a source of information and an evaluative resource. The women repeatedly emphasized that using the FORCE message board helped them re-exert control over their lives in order to avoid repeating the cancer histories of their relatives while maintaining good quality of life.

Although a recent analysis concluded that use of HRT after PO results in only a minor decrease in life expectancy (−0.17 to −0.34 years) if HRT is halted by age 50 [25], such an assessment was not available in the literature at the time of these postings, and data that are seemingly contradictory in their implications continue to accumulate [26]. The women participating in this thread had to decide whether to use HRT in the face of professionals' expressed concerns about initiating HRT before more clinical data were available or, in many cases, their physicians' outright rejection of the HRT following PO. The discrepancy between the women's preferences for at least low dose HRT and the professionals' reservations and resistance were seen as reflections of differences in the value placed on absolute risk reduction versus

quality of life. There was a definite sense that professionals minimized the implications of the women having to live with an abrupt surgical menopause, even though at the time HRT was routinely prescribed to unaffected women for relief of menopausal symptoms [27]. The perceived lack of empathy and unhelpfulness of medical professionals reinforced the women's feelings that their health predicament separated them from others. This sense of isolation bound them together on the FORCE website in an emergent community.

The women contributing to this thread built their own social structure by engaging in reciprocal and multi-participant conversations over time. They appeared to ignore the public nature of the web site and treated FORCE as their private, treasured and very personal social space. A crucial theme evident in their posts was the development of trust among FORCE sisters. Trust is among the core reasons why women find web based support groups so helpful. Our findings are consistent with recent web research that has shown that women highly value information and advice from other women with the same medical conditions and experiences, and trust the information they provide [20,28].

Moreover, the sense of trust and community engendered on this thread appeared to enable these women to make the unpleasant choices they faced with a degree of confidence they otherwise might not have felt on their own. These choices were then validated by multiple posts reinforcing the concept that what any individual woman finally decides is right for them. In this way, trust in the community translated to its individual members. The motto 'trust your body, trust yourself' is reiterated in different words in many posts.

The literature concerning the role of web-based health resources developed by consumers is limited but growing, and the thread we reviewed can be interpreted in light of this literature. First, the thread can be viewed in terms of how online communities develop a *collective intelligence* in the face of medical uncertainty [20]. The thematic strategies for doing so, *articles and article discussion*, *requests for advice and information*, and *sharing information* [29] were clearly evident in this thread. The women sought experiential information from other FORCE members, tracked down relevant scientific literature, consulted with experts, and shared both experiential and medical information about the specific physical and emotional changes and possible long term implications of early menopause on physical health and quality of life.

The present thread is also relevant to the concept of the *expert patient* and has broad relevance in terms of people developing the knowledge to maintain their health and manage illness, thereby having greater control over their lives [30]. Research suggests that women use the internet to circumvent professionals' control of access to

health information and its interpretation [31]. A growing controversy concerning the expert patient [32] revolves around whether it is possible for lay persons to actually renegotiate a more balanced relationship with medical professionals, rather than merely being burdened with responsibilities previously met by the health system. The women participating in this thread seem to fulfill the more empowering view of the expert patient by integrating personal and medical knowledge to renegotiate their individual relationships with medical professionals [33]. As Radin [20] reports, it is the 'mundane and profound exchanges, the poignant self-disclosures [and] the creative expression of solidarity' (p. 591) that develops the *thick trust* necessary to breach the health community's monopoly perspective on health information.

The FORCE web site provided a critical mass of women who faced the same daunting issues the opportunity to *talk* to each other in a primary group setting that they had created. This enabled them to share the process of making the decision to use low dosages of HRT on both cognitive and emotional levels. After individual decisions about prophylactic surgery and HRT were made, women tended to fade back into the FORCE community, although the thread they produced remains as a resource for subsequent women facing such decisions. In this way, their messages contributed to the construction of social norms for dealing with the impact of PO—a reference point for future generations.

We should be careful not to over generalize from this thread. These women are extraordinarily resourceful and at least some of them apparently already had exceptional access to both the medical literature and to high quality, responsive health care. The thread may have allowed them to spread these resources to others, but many high-risk women, likely the bulk of them in the community, will not find access to this thread and the website on which it is available, as approximately 39% of American women do not go online [34].

The present study has several other limitations inherent in the use of posts on a publicly accessible website as data [35]. The views expressed by individuals posting on this thread might not reflect the collective views of those who read the messages but did not post themselves. As was the case in this study, one individual can dominate a thread, and this may have created an ambiance that inhibited other participants from expressing differing views. Because it is difficult to verify the identity of people posting on the website and the same individual may submit messages under different pseudonyms, fewer women may have participated in this thread than was indicated by the number of screen names. However, this is likely to be minimal on the FORCE website, where many participants voluntarily register their email addresses.

Despite these limitations, the methodology used for this study has several strengths. The combined qualitative/quantitative data analytic strategy and extrapolation of themes from a Web-based message board improves on traditional focus groups and interviews by eliminating the constraints imposed by the presence of a researcher–observer and by facilitating sampling of a larger group over an extended period of time. This strategy allowed us to observe women's real-time descriptions of coping and problem solving, rather than asking for retrospective accounts. As well, the selection of this particular topic, PO and HRT, was determined by the frequency and duration of its discussion in the archives, and so reflects its relative importance among community members.

This paper presents the first findings from an ongoing study examining the self-identified issues of greatest concern to women at high-risk for HBOC who participate in the FORCE on-line community. To date, much of the existing psychosocial research involving the high-risk community has focused on the immediate emotional status and decision-making of women anticipating and receiving genetic testing [36,37]. We focused instead on the psychosocial and physical concerns of high-risk women as they negotiate difficult risk-management decisions surrounding the choice to undergo PO and/or to use HRT to reduce the negative impact of surgically induced menopause. Our findings highlight significant dissatisfaction with the medical community's sensitivity to these issues as well as frustration with the then current state of scientific knowledge regarding HRT. Efforts to address these issues should include clinical evaluation of the efficacy and safety of individualized bio-identical hormone alternatives for management of menopause in high-risk women, education of physicians in the community about the ongoing needs of high-risk women, and development of decisional aids to help women resolve the dilemmas and choices they face. Finally, as use of the internet for medical information continues to expand, it is important to consider the ways in which a web based support group can be integrated into a more holistic health care approach.

Acknowledgements

We gratefully acknowledge the assistance of Liisa Hantsoo and Carolyn Auwaerter. This research is supported by a grant from the Department of Defense (W81XWH-04-1-0562) to James C. Coyne, PhD.

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Editorial Manager(tm) for Journal of Genetic Counseling
Manuscript Draft

Manuscript Number:

Title: BRCA1/2 women renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure.

Article Type: Original Research

Section/Category:

Keywords: prophylactic mastectomy, reconstruction, stigma, web-based support group, self- image, self-disclosure, renegotiation of the self

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Manuscript Region of Origin:

Abstract:

BRCA1/2 women renegotiating a post-prophylactic mastectomy identity: Self-image and self-disclosure.

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Running Head: post-prophylactic mastectomy identity

ABSTRACT

The FORCE (Facing Our Risk of Cancer Empowered) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC) (Kenen, Shapiro, Friedman, Coyne in press). One of the most frequently discussed topics on the archived messaged board has been prophylactic mastectomy (PM) for women with a BRCA1/2 mutation. We reviewed the messages, over a 4 year period, of 21 high risk women and their “conversational” partners who originally posted on a thread about genetic testing, genetic counseling and family history. We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. The women sought emotional support, specific experiential knowledge and information from each other. They frequently found revealing their post PM status problematic because of possible negative reactions and adopted self-protective strategies of evasion and concealment outside of their web-based community. The FORCE message board was considered to be a safe place in which the women could be truthful about their choices and feelings. Results are discussed in terms of Goffman’s concepts “stigma” and “disclosure” and Charmaz’s concepts “interruptions,” “intrusions” and a “dreaded future”.

Key words: prophylactic mastectomy, reconstruction, stigma, web-based support group, self- image, self-disclosure, renegotiation of the self

INTRODUCTION

The average cumulative risk for developing breast cancer in women carrying a BRCA mutation is estimated to be 65% for BRCA1 and 45% for BRCA2 by the age of 70 (Antoniou, Pharoah, Narod, Risch, Eyfjord, Hopper, Loman, *et al.*, 2003). Although there are a number of strategies for managing hereditary breast and ovarian (HBOC) risk, including surveillance, chemoprevention, and prophylactic surgeries (ACS 2006; National Comprehensive Cancer Network 2004), individuals concerned about their risk may find it difficult to choose an option. Data concerning the risks associated with BRCA mutations, as well the risk reduction associated with various measures such as surveillance, chemoprevention and prophylactic surgery decision-making are emerging (DeMichele & Weber 2002; Grann, Jacobson, Thomason, Hershman, Heitjan, & Neugat 2002; Rebbeck, Lynch, Neuhausen, Narod, van't Veer, Garber, Evans, *et al.*, 2002; van Roosmalen, Verhoef, Stalmeier, Hoogerbrugge, van Daal, *et al.*, 2002; Van Sprundel, Schmidt, Rookus, Brohet, van Asperen, Rutgers, Van't Veer, *et al.*, 2005), but there are many pros and cons to each choice.

Prophylactic mastectomies (PMs) are increasingly suggested to very high risk women because the data indicates that the development of a first or contralateral breast cancer is reduced by approximately 90 -95% (Peralta, Ellenhorn, Wagman, Dagis, Andersen, & Chu, 2000; McDonnell, Schaid, Myers, Grant, Donohue, Woods, & Frost, 2001; Gui, Tan, Faliakou, Choy, A'Hern, & Ward, 2003; Harcourt, Rumsey, Ambler, Cawthorn, Reid, Maddox, Kenealy *et al.*, 2003). This operation is likely to be seriously considered by women who experience high anxiety about developing breast cancer and are particularly concerned about achieving the greatest possible reduction in risk, those

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4 who have young children and those who have had a close family member die of breast
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6 cancer (Meiser, 2005). A PM, however, is still considered to be a radical procedure
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8 (Bresser, Seynaeve, Van Gool, Brekelmans, Meijers- Heijboer, Van Geel, Menke-
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10 Pluijmers, *et al.*, 2006).
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16 Although overall satisfaction with bilateral or contralateral prophylactic
17
18 mastectomy has been reported to be very high, fewer women were satisfied with the
19
20 cosmetic outcome and a minority expressed feelings that their femininity and body image
21
22 were adversely affected (Hopwood, Lee, Shenton, Baildam, Brain, Lalloo, Evans, *et al.*,
23
24 2000; Lloyd, Watson, Oaker, Sacks, Querci Della Rovere, & Gui, 2000; Frost, 2005;
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26 Bresser, Seynaeve, Van Gool, Brekelmans, Meijers- Heijboer, Van Geel, Menke-
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28 Pluijmers, *et al.*, 2006; Lostumbo, Carbine, Wallace, Ezzo, *et al.*, 2006). Bresser *et al.*
29
30 (2006) suggest “that the absence of regrets despite the awareness of adverse
31
32 consequences reflect that the urge to reduce anxiety, remain healthy, and survive
33
34 supersedes any ambivalence regarding the possible negative outcomes of prophylactic
35
36 mastectomy/breast reconstruction in the long term” (p. 1681).
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45 Even though most of the women undergoing a PM were satisfied with their
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47 choice, some individuals in society consider an intervention such as a PM akin to
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49 mutilation (Press, Reynolds, Pinsky , Murthy, Leo, & Burke, 2005). Respondents in
50
51 Lloyd *et al.*’s study of women who had experiences a PM (Lloyd, Watson, Oaker, Sacks,
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53 Querci Della Rovere, & Gui, 2000) reported that common reactions from friends and
54
55 relatives were those of “shock” and “horror” (p. 477). Therefore, women who choose PM
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4 need to be aware not only of the many physical problems that frequently occur after
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6 surgery but of their own psychological reactions to the actual or perceived reactions from
7
8 others. Historically, stigmas have been attached to radical surgery (Kelly 1992). Thus,
9
10 those women choosing a PM are likely to find themselves experiencing tensions between
11
12 their expectations for the PM and reconstruction (if they decide to reconstruct), possible
13
14 stigma, and whether, or to whom, the PM experience is revealed. In this situation,
15
16 women need understanding and informed friends to talk to and a safe place in which to
17
18 express their feelings.
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24 The beneficial aspect of women's friendships has been well documented by
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26 others (Apter & Josselson, 1998; Aday, Kehoe, & Farney, 2006; Kroenke, Kubazansky,
27
28 Schernhammer, Homes, & Kawachi, 2006), and *Facing Our Risk of Cancer Empowered*
29
30 (*FORCE*), a nonprofit organization and associated website, is a safe place for these
31
32 women to discuss their feelings, decision-making and clinical management options
33
34 because it is the sole website specifically devoted to the community of women at risk for
35
36 hereditary breast/ovarian cancer. The *FORCE* organization, and message board in
37
38 particular, create an environment in which women feel free to *tend* (nurture) and *befriend*
39
40 each other at a time of stress (Taylor, Cousino, Lewis, Gruenewald, Gurung, &
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42 Updegraff, 2000; Taylor, 2002).
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49 In this paper we examine one of the topics most frequently mentioned by women
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51 posting on the *FORCE* archived message boards -- consideration of the physical,
52
53 psychological, and social consequences of PM during the decision-making, recuperation
54
55 and reconstruction process. We report on the women's feelings of loss, perceived stigma,
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4 tension between disclosing and concealing, and their need to renegotiate their sense of
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6 self and relationships with others.
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11 The Conceptual Framework
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13

14 We apply Goffman's (1963) concepts of "passing" or "covering" (hiding or
15
16 concealing) and discredited (immediately viewable) and discreditable (potentially
17
18 knowable) stigma. A *stigma* refers to a negatively evaluated condition or attribute that
19
20 sets the person apart from "normal" individuals in society (Fortenberry, McFarlane,
21
22 Bleakley, Bull, Fishbein, Grimley, Malotte, *et al.*, 2002). We combine these concepts
23
24 with Charmaz's (1991) concepts regarding the self and time. We discuss
25
26 "interruptions", "intrusions" and the idea that the sense of self is rooted in time as well as
27
28 in relationships. *Interruptions* are small and temporary part of one's life and *intrusions*
29
30 require time, accommodation and attention (Charmaz 1991). Charmaz uses these
31
32 concepts to help explain how everyday thoughts about behavior, presentations, and
33
34 interactions, become problematic and have to be renegotiated after a person becomes
35
36 chronically ill, disabled or is severely scarred. While a PM is different because the
37
38 prophylactic mastectomy/reconstruction process is undertaken by healthy women
39
40 attempting to avoid developing breast cancer, the concepts of "interruptions" and
41
42 "intrusions" and "dreaded future" are applicable in the PM case as well .
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50 We also investigate how women strategically use disclosure and concealment
51
52 strategies to manage the re-presentation of themselves (Hilbert, 1984; Druley , Stephens
53
54 & Coyne, 1997). In their studies, the researchers found that there is frequently
55
56 contradictory pressure to share and to conceal information about their feelings pertaining
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4 to their illness. “Dilemmas of whether or not to disclose illness information, and when,
5
6 how often, and how much to disclose are issues with which patients must continually
7
8 grapple” (Druley, Stephens, & Coyne, 1997, p. 512). This paper is concerned with
9
10 similar issues and addresses the tension between the PM decision and their renegotiation
11
12 of a post PM identity, particularly self-image and self-disclosure. Themes associated
13
14 with the everyday lived experience of undergoing a PM and reconstruction are to be
15
16 reported in a companion paper.
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23 24 **METHODS**

25 26 Sample

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28 We selected twenty-one women who posted on a two part thread about genetic
29
30 testing, genetic counseling and family history at the end of 2000 and beginning of 2001.
31
32 We chose this thread as our initial starting point because the messages concerned genetic
33
34 counseling, genetic testing and family history -- crucial factors that initiate the decision-
35
36 making process regarding clinical management choices namely surveillance versus
37
38 prophylactic mastectomy. We chose to follow the same women over time, rather than
39
40 investigate a larger group of women at one specific time because we wanted to study the
41
42 emotional complexity of the PM experience and to see whether there was cognitive and
43
44 emotional adjustment and reappraisal of their PM decisions as they became further
45
46 removed from the actual procedure.
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48
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52

53 We read these twenty one women’s posts regarding PM reconstruction during
54
55 the period January 2000 – March 2004, the last date the archived posts were available
56
57 when we first initiated this project. They posted 1171 times on the PM topic. These
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4 posts, however, did not describe the women's decision-making process or their actual
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6 PM operation, recovery or reconstruction in chronological order. The women often
7
8 discussed various incidents in the past when something in their present experience made
9
10 those experiences seem relevant. The women also were partners in "conversations" on
11
12 the message board, and thus their posts frequently were responses to other women's
13
14 comments. Therefore, we also read messages from women who posted specifically to
15
16 these 21 women in order to glimpse both parts of a conversation on this subject. These
17
18 "conversational partners" posted 328 times to the 21 women in our sample. All
19
20 messages are written verbatim including spelling and grammatical errors. Four dots
21
22 "... " are used when parts of the message have been deleted.
23
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29 The women ranged in age from their mid twenties to early fifties; most being in
30
31 their 30s and 40s. There were 17 women who had not developed breast/ovarian cancer,
32
33 referred to as *previvors* by the FORCE community, and 4 cancer survivors. One woman
34
35 started posting as a previvor but later developed breast cancer and started to post again.
36
37

38 Design

39
40 We primarily used qualitative analysis involving an initial identification of
41
42 themes in the messages discussing prophylactic mastectomy using an inductive process
43
44 involving coding and identification of recurring patterns, relationships and processes in
45
46 the data, emphasizing the participants' own accounts of their phenomenological and
47
48 social world (Pidgeon, 1996; Strauss & Corbin, 1994; Glaser & Strauss, 1967). We
49
50 developed a thematic account based on the women's postings on the message board in
51
52 order to identify various elements in the thread under investigation which might
53
54 otherwise remain hidden and to emphasize the meaning in human action (Beeson, 1997).
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Two of the authors used close reading and hand coding of the data until consensus was reached and all major themes were identified. This approach does not assume that there is only one measure of reality that is objectively grounded (Mathieson & Stam, 1995). In addition, we compiled the length of time and dates at which the women posted, the length of time they participated and the number of posts that they sent.

This study was approved by the University of Pennsylvania Institutional Research Board. In order to protect the privacy of women currently posting on the FORCE message boards, we only reviewed password protected archived messages. Furthermore, access to the archived material is provided by the executive director on a case by case basis. Posters were assigned pseudonyms. These provided an extra layer of protection because the women already chose pseudonyms as their posting identities.

RESULTS

Table I describes the characteristics of the posters and frequency of their postings. (See Table I.) The women in this sample varied greatly in the number of messages they posted about PM, the number of different women they addressed or answered, and the length of time they posted. A few women were mainly lurkers-- women who read messages but rarely contributed to the thread (Nonnecke, Preece, Andrews, & Voukour, 2004). The majority of women began posting at the time they were deciding whether to continue surveillance or undergo PM and stopped when they had finished their post PM reconstruction. During the time they posted, they actively supported each other emotionally and with experiential information. A few of these women posted briefly at a later time when they had a question or something was

troubling them. A couple of women continued to post for years. These women wrote about their dedication to FORCE and wanting to “return” the support they had received by offering their experiences to new FORCE posters who were now grappling with prophylactic decisions (Kenen, Shapiro, Friedman, & Coyne, in press).

Tension Arising from BRCA testing and Decision to Undergo PM; Psychosocial Aftermath

Self-Image and Interpersonal Relationships

The effect on self-image and interpersonal relationships frequently starts with a positive genetic test result (Kenen, Ardern-Jones, & Eeles, 2004). It can go on for years and often pervades the woman’s life while she decides how she wants to clinically manage her BRCA+ status. This can, in some cases, be considered a mental intrusion similar to an illness intrusion requiring time, accommodation and attention (Charmaz, 1991). The actual prophylactic mastectomy and reconstruction is experienced more as an illness interruption which is temporary and over when it has been satisfactorily completed (Charmaz, 1991).

Goffman (1963) also writes about how taken for granted aspects of what was formerly considered to be part of a normal life are no longer taken for granted. Irena reflects about something as simple as a hug. Hugs which were a major part of Irena’s emotional expression especially toward her children became problematic and resulted in “bruising” as an unanticipated and uncomfortable side effect of her hard breasts.

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4 Hard reconstructed breasts were a common complaint by women on the message
5
6 board.
7

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9I ended up switching to silicone a year later and have been
10 very happy. They are soft and I can lay on my stomach no
11 problem. My entire family is happier and no longer has
12 "boob brusing" on their bodies after long hugs. Seriously,
13 they got in the way of good hugs.
14 Irena
15
16

17 Irena also wrote about the two year interruption in her life from genetic testing
18 through reconstruction. She reflected that she was so immersed in her own BRCA+
19 condition that she considered this period as a void in her life that she could not get back.
20 She felt this keenly in terms of not being able to relish that time with her children. In this
21 case, the shift in relationship was almost like a temporary suspension.
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31 Mariella,... However long the process
32 I'm glad I did choose reconstruction and being on the
33 other end of the process I do see that it time stood still for
34 about a two year process [which includes the genetic
35 testing process through reconstruction process]. ... I did
36 day to day things for them [her children] but was unable
37 to relish in the time I was with them and remember every
38 action or face they made. I was so immersed in my
39 issues from finding out my status to having surgery and
40 recovering. However, I try to reconcile my feelings by
41 saying I may have lost say two years with them to gain
42 many many many more. However, it did create a void in
43 my life that I cannot get back.... Irena
44
45
46
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48

49 Feeling different- feeling loss of natural breasts

50

51 The fear of loss of femininity, sexual attraction and loss of sexual pleasure were
52 in the minds of many of the women. Liza feared her own reaction to her loss of breasts.
53 Lee J feared her husband's reaction. Before she actually underwent a PM, RY began to
54 grieve over an important part of her sexual experience with her husband that she never
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4 would get back. Her quote explicitly demonstrates the tension between the feelings of
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6 rightness about the decision to undergo a PM while concurrently grieving for aspects of
7
8 the aftermath - the loss of an important part of her sexual experience.
9
10

11
12
13 Just wanted to let everyone know that I am counting down the days until my
14 PM..... Getting a bit nervous. Not so much for the surgery (although that's a bit
15 scary) but for my reaction to loss of breasts. Reality, and my reaction to it, does
16 frighten me! I will keep everyone posted once I am up and around. Thanks,
17 Liza
18
19

20 Irena.... I am still extremely anxious about the surgery.
21 I also fear how my husband (of only 1 year)will react post
22 surgery.....How is he going to react when he sees my battered
23 body?Lee J
24
25

26 I have no doubts that based on what is available to BRCA
27 carriers today, a pm is very right for me. I am choosing life.
28 Yet, I am already grieving over what my husband of twenty
29 years and I will lose forever. I am convinced that we will still
30 enjoy a very satisfying sexual relationship, but I know that the
31 loss of my breasts (even with recon) will significantly change
32 everything. I don't worry that I will regret my decision,
33 instead, I think I worry that I wont be able to assimilate the
34 changes fully and enjoy my life, my body, and my husband as
35 much as I have until now.... RY
36
37
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41 Perception of self/other stigma

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43 Concealing through the use of clothing

44

45
46 When a person perceives a stigma attached to a body characteristic that can be
47
48 hidden, she can choose to reveal it or conceal it. This can be done verbally and through
49
50 the use of clothing. In Caitlin's case, it seems more of a feeling of self-stigma rather
51
52 than a stigma from a significant other. Even though Caitlin says she does not dwell on
53
54 how her new breasts look, three years after her reconstruction she admits that she is still
55
56 uncomfortable in the nude or "reveal" state even though her husband feels comfortable
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4 with her reconstructed breasts. The merest wisp of a cover such as a camisole top shifts
5
6 her to a happier “conceal” state.
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9

10 I am less self conscious in a tank top or camisole when I
11 am with my husband intimately, though he doesn’t mind
12 them. My pm was 3 years ago. I do love how they look in
13 clothes which is an upside. I am self conscious naked, but
14 don’t dwell on it, since I don’t feel my prior bc and
15 positive braca status left me with any alternatives.
16
17 Caitlin
18
19

20 However, it is how she looks in clothing, a more total concealer that makes her
21
22 feel very good about herself. While Caitlin feels a tension between reveal and conceal,
23
24 she actually feels little tension between the PM decision and its aftermath. She felt that
25
26 her previous breast cancer and positive BRCA status did not leave her an alternative to
27
28 PM.
29
30
31

32 Carin and Zoe were each delighted with their reconstructed breasts. Carin was
33
34 comfortable revealing her body to her husband and was delighted to hear that he found
35
36 her new breasts beautiful. The women frequently wrote about their need to feel sexually
37
38 attractive.
39
40
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44 Irena....I had my implants exchanged for silicone on
45 December 29, 2000. So far they are great. I can't feel the
46 implant inside my body, they feel like real breasts, no
47 sloshing and they look great! Even my DH told me that my
48 "new breasts" are beautiful..... Carin
49
50
51

52 Zoe normalized her new breasts by saying that in clothes nobody could ever
53
54 detect they were not real and that her plastic surgeon brought up the suggestion of a
55
56 “natural droop” to emulate real breasts. Her reference to her feelings that nobody could
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4 tell they were not real indicates that Zoe was probably a “concealer”, with strangers at
5
6
7 least.

8
9
10 Dear Babs,
11 I LOVE my implants..... I can say my only
12 "complaint" (although I think that word is far too
13 strong a word to describe my feeling here) is that
14 they are very firm. Not bad or uncomfortable, just
15 not as soft and squishy as my old breasts used to
16 be. Otherwise, I think they look great! The shape is
17 good, and in clothes no one would ever detect that
18 they weren't real....
19
20 | Zoe
21
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27 Lonnie Q was one of the few posters who decided not to reconstruct. In her case,
28
29 living in Hawaii, where the muumuu and cool and comfortable clothing were the norm,
30
31 made the decision not to have reconstruction more palatable. In addition, her husband
32
33 has been supportive of her decision. Thus, normal Hawaiian attire concealed all types of
34
35 body differences. This combined with being able to reveal her unreconstructed breasts to
36
37 her husband seemed to enable Lonnie to avoid feeling any self stigma or stigma from
38
39
40 others.
41
42
43

44 i am quite happy with not having the reconstruction and
45 being flat chested. my husband has been very supportive
46 with this decision. living in hawaii, the usual style of
47 clothing is cool and comfortable, and i am at ease going out
48 in public without any prostheses, besides the hawaiian
49 dress called the muumuu helps to hide all the different
50 body shapes and sizes.... Lonnie Q
51
52
53
54

55 Verbal Revealing / Verbal Concealing

56 Shifts in friendship and workplace relationships

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2
3
4 Several women wrote on the message board about family conflicts where some
5
6 family members felt stigmatized and refused to talk about the inherited breast/ovarian
7
8 cancer in their family. Many more women posted about dilemmas they experienced
9
10 regarding with whom they could be open and honest regarding their prophylactic
11
12 mastectomies. They indicated a lack of trust in how their friends would react. Mariella
13
14 complained that she was tired of having to process her friends' issues about her surgery
15
16 in addition to coping with the surgery itself. RY and Lorna found that their friends could
17
18 not keep a secret but passed it on instead. None of the women used the word stigma, but
19
20 talked about negative reactions or having to offer complicated explanations for their
21
22 prophylactic mastectomy decisions. But as Goffman stated, a "discreditable stigma" is
23
24 knowable and the knowledge eventually gets revealed and has to be addressed. In order
25
26 to help "cover" the true situation, the women devised white lies that were close to the
27
28 truth. They told about pre-cancerous conditions.
29
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37 I was ambivalent in the past about how much of my
38 "business" co-workers knew. And, once it's out, it's out. One
39 side of me wants to be honest, open and a role model. The
40 other side is tired of helping people process THEIR issues with
41 MY life issues.... Everyone has unique views and feelings
42 about these things. And, my views are not "the norm",
43 apparently, or I'd be OK with it, I guess. Anyway, after
44 dealing with issues openly, then others privately, I found I
45 prefer privacy.... Mariella
46
47
48
49

50 RY and Lorna indicated a lack of trust, yet an understanding of why friends
51
52 violated their confidence. RY realizes that in some sense she is stigmatized by her
53
54 decision to have a PM. She says that unless she gives what her friends feel is a
55
56 compelling reason, they think she is "nuts". Thus she has to renegotiate her identity with
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4 a white lie, the precancerous condition, and re-present herself with an acceptable
5
6
7 explanation for her operation.
8
9

10
11 Liza, your suggestion about saying it was "precancer" and
12 that due to family history the pm is recommended is also a
13 good choice for me. I've found when telling friends, that if
14 I don't follow up with a compelling reason, such as the
15 BRCA 1, they think I'm nuts. The precancer excuse may
16 give me a compelling reason without having to disclose my
17 genetic status! Randi, I have also found that some close
18 friends haven't been able to not share this important info
19 with their close support system. At first I was soooo
20 disappointed in them not keeping my confidence, but have
21 forgiven the discretion by remembering they also have to
22 process their feelings regarding this very emotionally
23 charged issue.
24
25 RY
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32 As the above quotes indicate many were ambivalent about being open about their
33
34 PMs and reconstructions. Zoe clearly perceived the differences in the way many women
35
36 in the general society perceive a mastectomy due to breast cancer and removal of a
37
38 healthy breast by a healthy woman on the basis of family history and risk. She said that
39
40 if she had had breast cancer she would never have considered hiding her surgery, but not
41
42 many people understand what "prophylactic" means.
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47 Hi everyone! Since I had my proph. mst w/ implant
48 recon. in May, I have been keeping it "secret".... Part
49 of me feels like I don't want to have to continue to lie to
50 most of the people around me (neighbors, church
51 groups, friends that I don't have a very close
52 relationship with) and that I would love their support as
53 I go thru all of this; after all, if I actually had HAD
54 cancer first, I would never consider "hiding" my
55 surgery from anyone. Then, part of me fears the
56 judgement people will likely place on me for making
57 the choices that I made.... Not many people even
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4 understand what a mastectomy is, much less what the
5 word "prophylactic" means!!Zoe
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9 A few of the women had bad experiences telling others about their PM and did
10 not want to expose themselves to negative and stigmatizing comments. Randi recalled
11 that most people were horrified that she had done this to herself. She and Zoe also chose
12 what Goffman refers to as taking the discredited stigma route. They chose alternative
13 narratives that they felt would present themselves in a more favorable light.
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21 Zoe- Let the urge pass and DON'T tell anyone else. I
22 am in the closet like you and wish I had told even less
23 people than I did. I really don't want the "lookie loos"
24 nor do I get any pleasure from the 'support' of others.
25 Most people are horrified that I did this to myself
26 (including a first cousin whose mother died of breast
27 cancer). Just lie about it, say you had the flu, that it's a
28 bad year whatever, I have a few friends who figured
29 out something was going on, but stopped asking and
30 forgot about it after a few weeks....
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34 Randi
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38 Reveal/Conceal: Intrusion into Mother/Children Relationship

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43 Disclosing to children their own BRCA+ status and choice of a PM has additional
44 implications. Several women wrote about not wanting to frighten their children and have
45 them worry that they would lose their mother. Aside from not specifically telling
46 children, not disclosing this information to their wider circle of friends and acquaintances
47 was another way of trying to insulate their children from learning this information.
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49 Caitlin chose the route of what Goffman refers to as making a condition discreditable
50 rather than discredited, hiding what might be considered a stigma instead of having her
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son face unpleasant fallout from gossip. She implied this by saying that she wanted to ensure the privacy of her son. She considered the FORCE message board a safe place to tell the truth about her choices and feelings. Women on the message board kept reiterating this theme. The befriend/tend function (Taylor, Cousino, Lewis, Gruenewald, Gurung, & Updegraff, 2000; Taylor 2002) was keenly appreciated by the posters.

Dear Josie, Choosing a pm is an enormous step, and anyone outside of our arena may have lots of difficulty processing it. I had no interest in having my general work place aware of the details of my surgeries.... Also for the privacy of my son, and my not wanting him to think he had a mother at risk of leaving him anytime soon, I had no interest in this being PTA chatter either. I am however a fairly active and grateful participant of this board, where I am most comfortable discussing life with a mutation and all its ramifications.... Best,
Caitlin

Telling pre-teen and teenage daughters involves the additional dimension of femininity and sexual attractiveness. Knowing that their mother is losing her breasts at a time when they are gaining them can be difficult for them to process. Katya poignantly writes about this. Katyas's breast cancer diagnosis was an intrusion into, and an interruption of, her previous relationship with her daughter at a sensitive time of her development. Her daughter's comments that she would be embarrassed if her mother lost her breasts when she was just developing her own seemed to indicate that the daughter would feel a stigma on behalf of her mother. Her "corrected" comment that she meant to say, "sad" instead of embarrassed could be construed that her mother would be losing much of her sexual attractiveness.

I often wonder about children's' ability to cope and make sense of all the cancer surrounding them in addition to

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4 making sense of their mom's going in for these "not sick"
5 surgeries. When I told my 11 year old daughter about the
6 results of my genetic testing and explained to her what
7 my follow-up options might be she said something that
8 deeply touched me. She said that she would be
9 embarrassed if I lost my breasts because she was just
10 getting hers and it wouldn't be fair. I asked her why she
11 chose the word embarrassed and she corrected herself
12 and said that she actually meant that she would be sad.
13 Looking back on my own response at age 12 to my
14 mother losing her breasts - I can see that she probably did
15 mean both embarrass and sad.
16 Katya
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21 Cognitive and Emotional Reassessment: Coming to Terms with the PM Decision

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23
24 Gradually, most of the women came to terms with both their BRCA+ status and
25 their post prophylactic mastectomy self. Despite the complaints and dissatisfaction with
26 their reconstruction that many of the women wrote about, the overwhelming majority of
27 women stated that the freedom from fear and the diminution of risk was worth the
28 problems associated with their PM. They reassessed their cognitive and emotional
29 perspective over time. Posts from RY illustrated such changes. She, as well as several
30 other women, felt that as an extra bonus that their breasts looked better and they had a
31 sexier shape after the reconstruction than before. RY, who missed the sensation in her
32 breasts and had a rough reconstruction period with several operations, viewed her good
33 outcome as compensation for all she went through and gave up.
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48 Faye, I, too, was unprepared for how painful the
49 expansion was at first (I know the shock), but your
50 muscles will relax and the vice grip will loosen. I still get
51 tightness and even back spasms, but all in all I am feeling
52 better.
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54

55After two kids, nursing, and 39 years, my breasts were
56 also kind of stretched out and saggy. I have to admit that
57 sometimes I feel a little guilty for enjoying the great way
58 my new breasts look in clothes. I even feel that I have a
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4 sexier shape without the clothes (although, of course,
5 there is no erotic sensation). I enjoy the perkiness, the
6 fullness, and not having to ever wear a bra! My husband
7 likes it too! I try to look at it as compensation for
8 everything I've gone through and gave up!
9 RY
10

11
12 Sally was just beginning to consider being less concealing about her PM. While
13 she still chose to remain silent, she wrote that she admired the women who were able to
14
15 be open about their PM and who helped educate the public as a result.
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21 I just want to applaud all the women who have chosen
22 to be open with their very personal issues and help
23 educate and inform the public in the process. I have
24 tended to be very private up til now -- time will tell
25 what I do in the future... Sally
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30 Caitlin probably reflected best the views of most of the women when looking
31
32 back at their PM experience. She wrote, "...I feel comfortable that I have done and
33
34 continue to do all that I can to reduce my risks and be here for my family"
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40 DISCUSSION

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43 Goffman and Charmaz mainly applied their concepts to illness and mental and
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45 physical disabilities. While a PM does not fit neatly into either category, it is similar
46
47 enough to usefully apply their concepts to gain a greater understanding of the situations
48
49 faced by women from HBOC families. Many of these women's presentations of self
50
51 after a PM were affected by changes in their breasts – looks and feeling- that influenced
52
53 their self-image and their willingness to disclose the PM to extended family, children,
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55 friends and co-workers. Weitz (2004) concludes that: "Those whose bodies differ in
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4 some critical way from the norm must develop a self-concept in the context of a culture
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6 that interprets bodily differences as signs of moral as well as physical inferiority. The
7
8 resulting stigma leads individuals to feel set apart from others” (p.177).
9

10
11 The women in this sample did not use the word stigma, but their decisions
12
13 regarding telling people and use of clothing to hide their breasts especially during the
14
15 reconstruction period indicated a discomfort in revealing their operation to acquaintances
16
17 and co-workers. They usually felt more comfortable about revealing to very close
18
19 friends. Currently, PM’s are more familiar to the general public because of the increase
20
21 in knowledge and media coverage about inherited breast cancer, but during the period
22
23 (mainly 2000-2001) that the women in this sample underwent a PM, it was a rarity.
24
25 These women were early adapters and norms about a PM were not yet clear (Kenen,
26
27 Ardern-Jones & Eeles, 2006). Thus it was difficult to determine how a friend or co-
28
29 worker would react. Some women in our sample complained that their friends could not
30
31 keep a secret and the information about their PM “got out”. The reaction from others
32
33 was unpredictable and this made it difficult for the women to take a chance with
34
35 revealing themselves. Yet a few women wrote about misunderstandings that were
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37 cleared up when they carefully and completely explained why they chose to have a PM.
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45 Goffman (1963) discusses two kinds of stigma - discredited and discreditable.
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47 A discredited stigma is one that is immediately obvious e.g., a severe hunchback, a
48
49 quadriplegic. An individual with a discredited stigma needs to manage social
50
51 relationships taking her stigmatizing condition into account. A discreditable stigma is a
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53 knowable one that is not immediately obvious e.g., severe burns or scars that are hidden,
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55 history of mental illness. In this case, information about the condition needs to be
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1 managed so that it remains unknown. A woman who undergoes a prophylactic
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6 mastectomy can hide the information from friends, relatives and possibly children, who
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9 do not see them without clothes. However, when having sexual relations with a partner
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11 or lover, the discreditable stigma becomes known and therefore discreditable. These
12
13 terms do not indicate that a condition in itself devalues an individual, but that some
14
15 members of society might view it that way.
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18
19 Goffman (1963) discusses “passing” and “covering” to indicate how individuals
20
21 deal with keeping a stigmatizing condition secret or more palatable. People make
22
23 assumptions about what a normal individual ought to be and a normal woman is expected
24
25 to have breasts – not to be completely flat chested or have surgically constructed
26
27 replacements. Goffman goes on to state that because of the great rewards bestowed on
28
29 those considered normal, almost all individuals will attempt to pass on some occasions
30
31 and those who cannot or do not want to “pass” will usually “cover”. Passing refers to
32
33 keeping a stigma unknowable, and covering refers to withdrawing some one’s attention
34
35 from a known stigma. We saw examples of both “passing” and “covering” in our data.
36
37 Non-disclosure was the main way the women chose to “pass”. In addition, some women
38
39 used what we call a hybrid form of passing/covering by using a close approximation of
40
41 the truth. For example, a few women told that they had gone in for an operation on a
42
43 pre-cancerous condition. A cancer related mastectomy was felt to be easier to disclose
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45 than a prophylactic one. In these cases, the women presented an alternative, and what
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47 they considered to be a more acceptable narrative.
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55 Clothing that hid scars and the shape of breasts was used to “pass” as were fake
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57 “boobs”. Clothing was also used to “cover”. One of the women years after her surgery
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4 wrote about how she still felt uncomfortable naked when she was intimate with her
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6 husband, even though he did not mind. She preferred to wear a tank top or camisole. In
7
8 this case, she was self-stigmatizing and used the camisole to deflect her husband's
9
10 attention from her reconstructed breasts. Another woman who did not reconstruct felt
11
12 comfortable in her environment where wearing loose fitting clothing was the norm.
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14

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16 The amount of discomfort so many women indicated in their discussions about
17
18 whether or not to disclose their PM says much about their own attitudes toward the loss
19
20 of one of the key elements of their feminine self. Furthermore if the women felt that they
21
22 had to be constantly on guard about revealing their PM, they might limit their social
23
24 network which in turn would emphasize feelings of isolation and being different (Kenen,
25
26 Ardern-Jones, & Eeles, 2006).
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31 The issue of potential stigma may be one of the reasons women expressed their
32
33 satisfaction and happiness with the FORCE message board. They write about the way
34
35 that they can be completely open about their decisions and emotions and are completely
36
37 supported. They do not have to worry about any potential stigmas and negative
38
39 reactions.
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42
43 Charmaz (1991) writes about the self in terms of relationships and time during
44
45 periods of chronic illness. Some women from HBOC families who develop
46
47 breast/ovarian cancer and develop metastasis or a new primary cancer fit the chronic
48
49 illness model. But most of the women face "chronic risk" instead. There are similarities,
50
51 however, between individuals facing chronic risk and those facing chronic illness
52
53 (Kenen, Ardern-Jones, & Eeles, 2003). In Charmaz's terms, many of these women prior
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55 to a PM, are trying to prevent their past and future from consuming them. Their thoughts
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4 about the past are filled with memories of family loss, and their future is clouded with
5
6 concerns about their own premature deaths (Kenen, Ardern-Jones, & Eeles, 2003;
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8 Lloyd, Watson, Oaker, Sacks, Querci Della Rovere, & Gui, 2000; Hopwood, Lee,
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10 Shenton, Baildam, Brain, Lalloo, & Evans, 2000). This is true for women who already
11
12 developed cancer as well (Ohlen & Holm, 2006). Women with a high risk for inherited
13
14 breast/ovarian cancer experience what Charmaz calls a “dreaded future”. Undergoing a
15
16 PM provides them with an “improved future”. But their “taken for granted future” is
17
18 gone. The women on the FORCE website expressed these themes and repeatedly
19
20 emphasized the value they placed on their “improved future” – one that reduced their
21
22 cancer risk by 90%.

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28 The women realized that they paid a high price for their PM decision in terms of
29
30 physical pain, mental anguish, shifts in social relations and feelings about themselves. As
31
32 Lloyd *et al* (2000) concluded, “The surgery meant that women were faced with having to
33
34 renegotiate their identity where they felt less of a woman, and accepted a new identity
35
36 with significantly reduced cancer risks” (p. 482).
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41 The events surrounding genetic counseling, genetic testing, the prophylactic
42
43 mastectomy and reconstruction appeared to be the times, events and experiences that
44
45 became anchored to the selves of the women in this study. The earlier chronic
46
47 intrusive thoughts and interruption of normal life during the PM and reconstruction
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49 period are over, but the marks on their bodies and lack of sensation in their nipples
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51 and breasts remain with them and remind them of the past and their former taken for
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53 granted future.
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4 The process from the decision to undergo a PM through reconstruction,
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6 lasted months and often years, and frequently involved both cognitive and emotional
7
8 reappraisal. Subsequent to their final reconstruction operation, most of the women
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10 stopped posting and several specifically said that they wanted to move beyond the
11
12 threat of a cancer dominated life. Despite moments of sadness, but not regret, the
13
14 women in this study who chose a PM felt that they made the correct choice in doing
15
16 whatever was possible to live in an “improved future”. They were willing to pay the
17
18 price of lost body parts and loss of some sexual pleasure for a future free of the
19
20 previously encompassing fear. Their aim was to return to normal and they achieved
21
22 this as much as possible.
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31 Limitations

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33 Using messages on a publicly accessible website as data involve certain
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35 inherent limitations (Jacobson, 1999). Individuals posting on the PM threads who
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37 discuss self-image, self-disclosure and stigma might not reflect the collective views
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39 of either those posters who do not mention these issues or those who read the
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41 messages but do not post. While web based support group data has the advantage of
42
43 being natural, rather than in response to researchers’ questions, the disadvantage is
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45 that the researcher is not able to focus questions and probes regarding specific issues
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47 of interest. Furthermore, this is a small, exploratory qualitative study and the
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49 findings cannot be generalized to the larger population of women carrying a
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51 BRCA1/2 mutation.
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Clinical Implications

The influence of the larger social context on women from HBOC families is a neglected area of investigation and requires both further research and a greater understanding by geneticists, genetic counselors and genetic nurses working with high-risk women. The experiences of these women living with PM highlight some often neglected psychosocial issues that need to be taken into account in decisional support and follow up of other women in this predicament.

Results from this study indicate that worry about how their PM decision is received colors the women's relationships with individuals in her social world – colleagues, acquaintances, church member etc. in addition to family and friends. Whether or not to disclose their PM becomes problematic for some women. Thus, the content of counseling courses required of health professionals caring for women from HBOC families should be expanded to include the effect of other members of a woman's social world. Furthermore, because the norms of the society are involved, simply counseling the women from HBOC families is not sufficient. Interdisciplinary approaches to the education of other professional groups and the general public are also required to ease the path of women from HBOC families who choose the PM route.

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Table I

Characteristics of the Posters and Frequency of their Postings.

Pseudonym	Pre/Survivor	Dates	Length	# Posts
Caitlin	Survivor	11/00–3/04	3y,5m cont.	184
Faye	Previvor	12/00	0y,1m	6
Flo	Previvor	3/00	1 post	1
FR	Previvor	1/01-3/01	0y,3m	8
Ilene	Previvor	6/02-10/02	0y,2m	2
Indigo	Previvor	5/00-7/00; 8/03-10/03	2y,3m; 0y,3m	55
Irena	Previvor	8/00-3/04	3y,8m	202
Katya	Survivor	7/00-12/00; 1/04-3/04	0y,6m; 0y,3m	14
Liza	Previvor	7/00-6/01; 10/02	1y,0m; 1 post	35
Lonnie Q	Survivor	12/00; 5/01	0y,1m; 1 post	3
Lou	Previvor	5/00-3/01	0y,11m	24
Mariella	Previvor	11/00-4/01	0y,6m	89
Parcy	Previvor	11/00-4/02	1y,6m	26
RA	Previvor	9/00-1/02; 6/03-8/03	1y,5m; 0y,2m	51
Randi	Previvor	1/00-3/01; 9/02; 11/02	1y,3m; 1m; 1m	65
Rina	Previvor	1/01-7/01	0y,7m	7
RY	Previvor	8/00-10/01; 9/02; 2/03	1y,3m; 1post; 1post	97
Sally	Previvor	8/00-1/02; 5/03; 9/03; 3/04	1y,6m; 0y1m; 2posts; 1	116
Ursula	Survivor	6/00-3/02	2y,9m	81
Wanda	Previvor	11/00-5/01; 10/03	0y,7m; 2posts	12
Zoe	Previvor	4/00-3/02; 1/03	1y,11m; 1post	93

Acknowledgments

This research is supported by a grant from the Department of Defense
(W81XWH-04-1-0562) to James C. Coyne, Ph.D.

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Women's Attributions of Mood and Cognitive Changes Following Prophylactic Oophorectomy

Liisa Hantsoo, James C. Coyne, Susan Friedman, Steven C. Palmer

Women at elevated risk for hereditary breast and ovarian cancer who undergo prophylactic oophorectomy (PO) face physical and psychosocial changes more bothersome than those in natural menopause. Research has focused on body image and feelings of lost femininity following PO. However, negative affective and cognitive difficulties have been reported, as have positive changes such as decreased anxiety. It is unclear, however, whether these changes in affective and cognitive experience are attributed to alterations in hormone functioning, risk of cancer, or other factors. Understanding attributions for changes is important, as these influence satisfaction with decisions to undergo PO as well decisions about symptom management. We examined attributions of cognitive and affective changes among women who had undergone PO via content analysis of more than 5000 postings on an internet-based discussion board (FORCE). Discussions of changes in mood and cognition since PO were categorized according to valence and attribution of change, yielding 141 unique postings. Results indicated that women posted about as often concerning positive mood and cognition changes (38%) as negative changes (43%). However, regardless of whether changes were positive or negative, they were 3.2 times more likely to be attributed to hormonal causes than nonhormonal causes. Among postings by women reporting positive changes, 83% attributed this to hormone replacement or non-hormonal causes (e.g., exercise, antidepressants), while among women reporting negative changes, 51% were attributed to hormone ablation. While women were about equally likely to attribute positive (72%) or negative (69%) changes to hormonal effects, negative experiences were more often attributed to loss of hormones (44%) than were positive experiences (17%). Women who experience negative changes following PO may consider utilizing contraindicated hormone replacement to obtain more positive outcomes.

D-34

THE PENN-F.O.R.C.E. HELPLINE: REACHING WOMEN AT RISK FOR HEREDITARY BREAST CANCER IN THE COMMUNITY

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The Abramson Cancer Center and Facing Our Risk of Cancer Empowered (FORCE) joined in December of 2003 to launch *The Penn-FORCE Helpline*, a peer-staffed, toll-free information and support service for individuals concerned about their risk of hereditary breast and ovarian cancers (HBOC). The goal of the Helpline is to reach geographically dispersed community-residing individuals with concerns revolving around issues of genetic risk, risk management, and prevention in order to provide information, health service referrals, and peer-support. The present study evaluates the effectiveness of the Helpline for meeting the needs of these individuals and documents the range of problems for which assistance was sought.

We report data collected during the first six months of the Helpline. Of 233 callers, 127 consented to participate in the study and 117 completed follow-up interviews. Callers were primarily women with a family or personal history of cancer, women who were BRCA1/II positive, and members of families with a known mutation. Calls centered on concerns about risk status, information about genetic counseling and testing, information about prophylactic surgeries and breast reconstruction, concerns about insurance coverage and privacy, and information on pragmatic management of postsurgery symptoms. The majority of callers (88%) reported complete satisfaction with the outcome of their call, 93% recommended the Helpline to others, and 30% reported uptake of health services related to risk management following their Helpline call. The Helpline is an effective tool for disseminating information about HBOC to the high-risk community.

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D-35

PERCEIVED HEALTH AND INTERNET INFORMATION USE AMONG WOMEN WITH BREAST CANCER

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¹Economics, Brooklyn College, Brooklyn, NY.

A. Question: Is perceived health associated with Internet health information use among women with breast cancer?

B. Sample: 143 women with breast cancer

C. Independent Measure: How do you see your health? (Separate categories of poor/fair, very good, and excellent). Dependent Measure: Internet use for breast health/women's health information. (yes/no)

D. Summary: The Internet has become a popular source for information about breast cancer. Three community studies studied the relationship of health status to Internet health information use. There are conflicting results with one study finding a relationship for poorer perceived health, another for better perceived health, and another no relationship. No studies exist for this relationship among women with breast cancer. Women with breast cancer completed questionnaires regarding demographic information, perceived health, and Internet health information use. Logistic regression analysis was conducted with excellent perceived health as the reference category. Besides the independent measure of perceived health status, covariates included age, education, income, length of time since diagnosis, and stage of breast cancer. Poor/fair perceived health was related to Internet health information use (odds ratio=5.3, $p<.05$) while very good perceived health was not (odds ratio=1.1, $p>.05$). These results suggest that among women with breast cancer, those with poor/fair perceived health are seeking health information from the Internet about their disease while those with very good/excellent perceived health are less likely to use the Internet as a health information resource.

E. Conclusions: Public health information and treatment interventions promoted through the Internet may better address the needs of women with breast cancer who have poor/fair health status as compared to those with very good/excellent health status.

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D-36

KIDNEY RECIPIENTS' INTEREST IN TRANSPLANTATION HEALTH EDUCATION

Amy D. Waterman, Ph.D.,¹ Ann C. Barrett, M.P.H.,¹ Sara L. Stanley, M.P.H.,¹ Mark A. Schnitzler, Ph.D.,² Barry A. Hong, Ph.D.,³ and Daniel C. Brennan, M.D.⁴

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To develop optimal transplantation education, we assessed 304 kidney recipients' interest in information about living donation, transplant surgery, transplant-related psychological concerns, Internet education, and recipient mentor discussion. After completing a mailed survey (67% response rate), multivariate logistic regression was conducted to identify demographic predictors of education interest.

Recipients were Caucasian (86%) and male (58%), with deceased donor transplants (52%). Recipients with *deceased* donor transplants wanted information about donor (90%) and recipient (76%) surgeries, recipient psychological concerns (80%), and mentor discussions (70%). Recipients with greater than a high school education wanted more information about donor psychological concerns (OR=2.59, CI=1.31, 5.12), living donation (OR=2.70, CI=1.36, 5.36), and mentor discussions (OR=2.53, CI=1.25, 5.14) than recipients with less education.

Recipients with *living donor* transplants were interested in education about donor (96%) and recipient (94%) surgeries, and common recipient (89%) and donor (76%) psychological concerns. Recipients who were < 55 years wanted more information about the donor surgery (OR=20.36, CI=2.37, 175.22) and Internet transplant education (OR=18.24, CI=2.07, 160.71) than recipients ≥ 55 years. Patients on dialysis (OR=2.52, CI=1.21, 5.25) were more interested in speaking with mentors than patients not on dialysis.

After explaining the transplant surgery, patients still have fears about transplantation that need to be addressed through discussion and education. Younger and more educated patients want more living donor education.

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D-37

WILL BEHAVIORAL MEDICINE RANDOMIZED CLINICAL TRIALS (RCTs) EARN AN A?

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Evidence-based clinical practice guidelines reserve their strongest endorsements for treatments supported by high-quality RCTs. Policy impact is therefore maximized for trials rated high on quality. We coded the analytic quality of all behavioral medicine RCTs ($n=74$) published between January 2000 and June 2003 in 3 psychology journals *Annals of Behavioral Medicine*, *Health Psychology*, *Journal of Consulting and Clinical Psychology* and 2 medical journals (*Journal of the American Medical Association*, *New England Journal of Medicine*). Cochran-Mansel-Haenszel analysis of 10 dichotomous criteria indicated that RCTs reported in medical journals surpassed those in psychology journals on overall analytic quality, $\chi^2(1) = 25.27$, $p < .0001$. Specifically RCT reports in medical journals more often defined a primary outcome ($p < .001$), provided a sample size rationale ($p < .001$), gave the denominator used in analyzing the primary outcome ($p < .01$), declared using intent-to-treat (ITT) analyses ($p < .01$), accounted for missing data in analyses ($p < .05$), and reported both ITT and per protocol analyses ($p < .05$). Use of the CONSORT reporting guidelines by medical journals probably explains the higher analytic quality ratings of RCTs reported there. Adoption of CONSORT by psychology journals is expected to improve the quality and impact of the behavioral medicine RCTs they report.

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