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Motivations, Concerns, and Experiences of Women Who Donate Normal Breast Tissue

Eileen F. Doherty¹, Erina L. MacGeorge², Traci Gillig³, Susan E. Clare⁴

¹Marymount Manhattan College, New York, New York, USA

²Pennsylvania State University, University Park, Pennsylvania, USA

³University of Southern California, Los Angeles, California, USA

⁴Northwestern University, Chicago, Illinois, USA

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Corresponding Author: Eileen F. Doherty, Department of Communication Arts, Marymount Manhattan College 221 East 71st Street, New York, NY 10021, USA

Phone: (585) 506-7558

Fax: 212-517-0528

Email: edoherty@mmm.edu

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Abstract

Background: The Susan G. Komen for the Cure Tissue Bank at the IU Simon Cancer Center (KTB) was established in 2007 with funding from Susan G. Komen for the Cure® to provide scientists with a resource for normal breast tissue. To date, nearly 3,500 women have donated their healthy breast tissue to the Bank, but little is known about their perspective. This study was designed to examine their motivations, concerns, and experiences.

Methods: We conducted brief interviews with donors ($n = 221$) to investigate their donation-related motivations, concerns, and experiences. Donor responses were coded and quantitatively analyzed (descriptive statistics and chi-square).

Results: The most frequent motivation to donate (48% of donors) was personal connection to a breast cancer patient/survivor. A majority of donors (60%) were unconcerned about donation prior to the event; reported concerns included pain, fear, and dislike of surgical procedures. The most frequent positive experiences were minimal pain and positive behavior by KTB staff and volunteers. A majority of donors (61%) reported no negative experience, but reported negative experiences included the biopsy machine and anesthetic. Younger donors (ages 18-24) reported more concerns and negative experiences than older donors (25+).

Conclusions: Donors of healthy breast tissue are motivated by survivor connections and the ability to help by donating. Their concerns and experiences are relatively positive and consistent with undergoing a minor surgical procedure. Younger donors have more concerns and negative experiences.

Impact: Findings from this study can inform recruitment campaigns and donation procedures for banking of healthy tissue.

Introduction

With breast cancer research increasingly focused on risk, early detection, and prevention (1) the Susan G. Komen for the Cure® Tissue Bank (KTB) at Indiana University (komentissuebank.iu.edu) has emerged as a unique resource for scientists interested in working with annotated samples of normal breast tissue (2). The first bank of its kind, worldwide, the KTB enrolls healthy donors who provide questionnaire data, blood, and up to four breast tissue samples, which are prepared as both formalin fixed paraffin embedded and frozen tissues (2). Samples are accessible to researchers worldwide through a proposal submission, review, and approval process. Recent studies based on KTB data have begun to demonstrate the value of this resource in research examining triple negative breast cancers (3), telomere fusions in early breast carcinoma (4), histologic characterization of normal breast tissues (5), serum microRNAs as biomarkers in breast cancer (6), the effect of the menstrual cycle and hormonal contraception on DNA expression in the normal breast epithelium (7), and phenotypic plasticity in normal breast tissue (8).

The KTB donation process is administered by medical personnel and volunteers, and takes approximately one hour from start to finish, starting with informed consent and medical history, continuing with a blood draw and the tissue acquisition procedure, and finishing with a recovery period. The tissue acquisition, removing about 1 gram of tissue, is taken from one breast and is performed by a surgeon or radiologist with a needle and local anesthesia. Donors typically experience some bruising and minimal scarring following the procedure, although individual experiences vary. The continued success of the KTB and the development of additional banks of normal tissue for scientific research depend on recruitment of women willing

to go through this process (9). Although a great deal is known about the psychology of recruitment for other types of prosocial donation (10-13), banking of normal breast tissue makes unique demands. In contrast to banking of cancerous tissue, which would have been removed anyway, donors have a medically unnecessary invasive procedure, which is also considerably more time-consuming and invasive than a blood draw. There is also no immediate or direct benefit of the donation (vs. blood, marrow, or organ donation, or clinical trials). Normal tissue banking is also distinct from participation in clinical trials, where there is usually a perceived or actual potential benefit to the participant (14). Finally, donors are requested to provide broad consent to permit the use of the obtained samples by any scientist approved by the KTB.

To date, KTB staff and volunteers have conducted over 35 donation events amassing just under 3,800 tissue donations, and most of those donations were made by women from the Indianapolis metropolitan area and other Indiana communities. Initial skepticism about the success of such events has been refuted (9), and the KTB's careful protocols have protected both their donors and the integrity of the scientific enterprise (2). However, there have been only anecdotal reports on their donors' experiences, motivations, and concerns (15). Additionally, it has become evident that donations are coming more frequently from older women. Because there are important parallels between normal aging and the development of cancer (16), it is critical for the KTB to provide scientists with tissue from across as much of the lifespan as possible—and therefore essential to understand differences between younger and older donors.

As part of a broader effort to evaluate and improve the KTB's donor recruitment campaign, we interviewed donors at three donation events, with a focus on how they learned about the KTB and the donation event, their motivations for and concerns about donating, and their first-hand experiences of donation. Due to targeted recruiting at local universities for two of

the events, it was possible to examine differences between donors under the age of 25, and donors 25 or older. Although there will certainly be differences between women who have already chosen to donate and those who have not yet donated (or are unwilling to do so), the population of donors is an accessible source of preliminary insight into the reach of the existing campaign, characteristics that motivate donation, concerns that may inhibit donation, and donation experiences that can be replicated or improved. This information is not only relevant to improving the KTB's continued recruitment efforts, but also provides baseline information for other organizations seeking to develop normal tissue banks.

Materials and Methods

Participants

Participants were 221 women who had just donated breast tissue at one of three tissue donation events, which occurred at three different cities in Indiana over a one-year period. 77% percent of the donors at the first event (Lafayette), 84% of donors at the second event (Indianapolis), and 58% of the donors at the third event (Fort Wayne) participated in the study. In most cases, reasons for non-participation are unknown, but included lack of time.

Demographics. Participants ranged in age from 18 to 77, with a mean age of 38 and a median age of 36. 30% of the sample was between 18 and 24; most of these were college students. The vast majority of participants reported Euro-American ethnicity (204, 92.3% “Caucasian” or “White”); the remaining participants reported African-American, Asian-American, Hispanic/Latina, or other ethnicities. Most donors (83.8%) had a “survivor connection”: they knew someone who had survived or died from breast cancer. Of those surveyed at the second and third data collections, 53% had a blood relative with breast cancer.

Procedure

As donors completed their recovery period, they were directed by event staff to a check-out area where they received post-operative instructions and refreshments. At this time, they were also told that a research team was conducting a survey—they referred to it as the “exit interview”—and pointed out the authors (and other research assistants) at a table.

Donors who indicated willingness to participate were taken through an oral consent protocol that emphasized (1) the voluntary and anonymous nature of participation, (2) the distinction between donating and participating in this study (explaining that the data sets were entirely separate), and (3) the freedom to refuse answers to any questions. Members of the research team interviewed donors individually and immediately recorded their responses by typing as much of what donors said as was possible into an Excel file; interviews were not recorded. This approach was selected to minimize donor time and effort, and to avoid unnecessary risk to donors’ privacy.

The interview questions addressed how participants had been recruited to the donation event, their motivations for donation, concerns they had prior to donation, and how they would describe the donation experience to others. Participants were also asked their age, ethnicity, and whether they knew anyone who had survived or died from breast cancer. Following the first donation event, the research team expanded the interview protocol to include a question about whether women had blood relatives who had survived or died from breast cancer, and whether pre-donation concerns were addressed by the KTB staff or volunteers before they donated. In addition, interviewers began to include the word “surgery” in questioning about donors’ experiences in order to elicit responses to the surgical procedure rather than generic reactions to

the donation event as a whole. Due to the change in this question, our subsequent analysis of donors' experiences is based on the more detailed data collected at the second and third donation event. All procedures were approved by the Institutional Review Board at Purdue University.

Classification and coding. Participants' reports of how they were recruited were highly objective, so the second author classified these reports into categories rather than undertaking a formal coding process. Participants' more subjective motivations, concerns, and experiences were all coded into categories using the same general procedure. After reviewing the data, the authors developed a set of mutually exclusive categories to classify participant responses to these questions (see Tables 1-5). Two sets of categories were developed for coding experiences, one positive, and one negative (Table 4 and 5). The first and second authors coded a 20% random sample of reported motivations and concerns, and two 10% random samples of experiences (coding one set for positive and the other for negative experiences). Cohen's kappa was .86 for motivations, .96 for concerns, .79 for positive experiences, and .72 for negative experiences. Disagreements in the reliability samples were resolved through the discussion, after which the first and second authors each completed half of the remaining coding.

Results

Recruitment

As shown in Table 1, donors were recruited through a variety of media, including traditional media (television, newspaper, and radio), electronic media (Facebook, work websites), e-mail, and posted flyers. They also reported being recruited through presentations (e.g., at sorority meetings), events (e.g., Black Expo in Indianapolis), and personal contact. There were significant differences in the frequency of recruitment through these means, $\chi^2 = 77.78$, with personal contact most frequently reported, and flyers and e-mail least frequently reported. There

was a significant difference in recruiting media reported as a function of age, $\chi^2 = 50.93$, $p < .001$.

Donors aged 25 or older were notably more likely to have learned about the event from traditional media (30% vs. 4.5%), whereas younger donors were notably more likely to have learned about the event from a presentation or event (20% vs. 5%). The latter is consistent with most of the younger donors having been recruited through college groups.

Motivations

Results showed that women's motives for donating included having a personal connection to a breast cancer survivor, or patient,; a desire to help the "cause" against breast cancer; a desire to support breast cancer research or advocate for breast cancer patients; being persuaded to donate by others; helping future generations; gratitude or perceived luck at not having had cancer; and being a cancer survivor. There were significant differences in the frequency of these motivations, $\chi^2 = 292.20$, with a personal connection to a breast cancer survivor being most frequently reported motivation. Being grateful for not having cancer or being a cancer survivor oneself were least frequently reported. There were no significant differences in motivations as a function of age, $\chi^2 = 11.58$, $p > .11$. We anticipated having a survivor connection might affect reported motivations, and a chi-square analysis supported this proposition, $\chi^2 = 34.89$, $p < .001$. 55% of donors with a survivor connection reported this as their motivation for donating, as compared to 10% of donors without this connection.

Concerns

There were significant differences in the frequency of reported concerns prior to donation, $\chi^2 = 402.00$. This finding clearly results from 60.2% of donors answering "none" in response to this question. Other responses included concerns about pain, discomfort, or weakness; being nervous, anxious or afraid; disliking surgical procedures (especially, the use of needles and the

sight of blood); being uncertain about what would happen. Some donors mentioned they were concerned because others were concerned. There were significant differences due to age in the concerns expressed, $\chi^2 = 22.12$, $p < .002$. The most striking difference was that 68% of the donors aged 25 or older said “none,” vs. 41% of donors under age 25. Nervousness, anxiety, or fear were also more likely to be mentioned by youth donors (14% vs. 5%), as was having a concern about needles or blood (17% vs. 4%). Having a survivor connection did not significantly affect reported concerns, $\chi^2 = 5.44$, $p > .49$.

At the second and third donation events, donors who indicated having had a concern prior to the donation event ($N = 52$) were asked whether this concern had been addressed by the KTB staff or volunteers before they donated. 92% ($N = 48$) indicated that their concerns had been addressed; the other 8% indicated that the concern had not been addressed, but also that they had not expressed the concern to the staff.

Positive and Negative Experiences

When asked how they would describe their experience to a potential donor, 87% of donors reported some kind of positive experience and 61% reported some kind of negative experience. A majority of donors reported both a positive and a negative experience, with only 9 donors reporting only negative experiences. There were significant differences between categories of reported positive experiences, $\chi^2 = 13.58$, $p < .001$; the most often reported positive experience was minimal pain, followed by positive behavior from staff and volunteers. “Other” positive experiences included “this is a step toward the future” and “everyone claps for you” (referring to the congratulatory applause of KTB staff and volunteers). There were also significant differences between categories of reported negative experiences, $\chi^2 = 177.49$, $p < .001$, but this was primarily driven by the large group who reported no negative experience. Additional

categories of negative experience included the biopsy machine (noise), anesthetic, and “other.” This category included general descriptions such as “a little scary” and “nervous,” as well as two reports of faintness. Age did not affect the *type* of reported positive experience, $\chi^2 = 4.92$, $p > .295$, or reported negative experience, $\chi^2 = 6.94$, $p > .139$. However, young donors were more likely to report *any* negative experience than were donors over the age of 25 (51% vs. 29%), $\chi^2 = 5.18$, $p < .02$. Of the 12 donors who reported only negative experiences, three reported an experience with the biopsy machine, four with the anesthetic, and five reported something coded as “other,” all referring to pain, discomfort, or dizziness.

Discussion

The current study was designed to assess the motives, concerns, and experiences of KTB donors. This information not only provides a foundation for improving the KTB’s continued recruitment efforts, but also provides useful information for other organizations seeking to develop banks of normal tissue.

Donor Demographics and Recruitment Channels

In terms of ethnicity, donors in the current study were similar, but not fully representative, of the total sample of women who have donated breast tissue thus far. Of approximately 3,500 women donors prior to March 1, 2014, 76% were White, 16% were African-American, 3% were Asian, and 5% identified as American Indian/Alaska Native, Native Hawaiian or Pacific Islander, or “Other” (J. Henry, personal communication, February 27, 2014). Our study’s lower percentage of non-White participants is attributable to conducting more than two-thirds of our interviews in Lafayette and Fort Wayne, where there are smaller minority populations. However, even in Indianapolis, recruiting women of color for breast tissue donation continues to be the most significant challenge for the KTB (J. Henry, personal communication, February 27, 2014).

Indy's "SuperCure", a donation event supported by the 2012 Super Bowl Host Committee, achieved a 36% percentage of African-American donors, suggesting that associating the KTB's efforts with major sporting events and the imprimatur of African-American opinion-makers is successful at recruiting donations from women of color. Future research should focus directly on the motivations, concerns, and experiences of minority donors and effective strategies for encouraging donation.

In the total sample of KTB donors, most (86.5%) were over the age of 25 (J. Henry, personal communication, March 2014). We attribute the greater representation of younger women in our sample to targeted recruiting through college student organizations, especially sororities. These donors provide an essential group for comparing the motivations, experiences, and concerns of younger and older women, but also illustrate the challenges involved in recruiting younger donors. Future research might be targeted at determining what donor recruitment strategies are most influential for younger donors. We were not able to determine whether our study's donors were similar with regard to having a blood relative with breast cancer because the KTB's data includes only first-degree blood relatives (22% of the 3500 donors reported having at least one first-degree blood relative who had breast cancer).

Donors were recruited through a variety of channels, with personal contact and traditional media topping the list. Traditional media had better reach for donors aged 25 and up. Data collection for the current study took place shortly before the KTB established a Facebook and Twitter presence. Currently, the KTB uses these media to provide information (e.g., about upcoming donation events), but does not use them for direct recruitment. Instead, the KTB is now relying on an "interested donor" list as a primary source of donors. The list is the result of

the 2012 “Super Cure” recruitment efforts, and it currently includes the names of over 2,000 women who have expressed interest in donating.

Motivations

The prevalence of a survivor connection, survivors as a motivation for donation, and the association between the two indicate that a survivor connection is a key motivator for many instances of healthy breast tissue donation. However, recruiting on the basis of survivor connections could also result in overrepresentation of tissue samples from women with higher risk of breast cancer, something that is clearly problematic for a bank of normal breast tissue. Accordingly, the KTB needs to continue seeking effective strategies for recruiting donors who do not have a survivor connection (or, at least, where the connection is not to a first-degree relative). The other most frequent motivation was “helping the cause,” which appears to reference language that is often used by Komen and other groups that focus attention on breast cancer. It may be useful to determine more specifically what “helping the cause” means to the women who name it as their motivation, and how it can be utilized to engage other donors. Women who noted that their motivation was “persuasion by others” speak to the power of social networks and interpersonal influence strategies in the success of donation campaigns (17). Because younger and older donors did not differ in their reported motivations, it may be possible to design campaign messages that will be equally effective for both audiences. However, differences in their concerns and experiences suggest some targeting will be necessary.

Concerns

A substantial percentage of donors expressed no concerns prior to donation. This finding can be attributed in part to the effectiveness of the information available on the KTB website and in e-mails sent to registered participants. However, it is essential to recognize that the finding

must underestimate the concerns that exist in the population of women who have not yet donated (18). In addition, younger donors were more likely to express concerns than those over the age of 25, especially concern about nervousness, anxiety or fear, and concern about the surgical procedure (needles and blood). This is unsurprising, since any woman might well be concerned about unfamiliar surgical procedures and their consequences, and experience with surgical procedures tends to increase with age. However, it does indicate the importance of addressing these concerns as part of the recruitment process, for effective recruiting, and especially for younger donors.

Future studies should examine affective influences on donation, including donation anxiety (19-21) and anticipated regret (22), and consider how to best resolve or reduce concerns in ways that encourage women to donate. One important step that the KTB has taken in an effort to allay donor concerns is the creation of a three-minute long YouTube video that follows one woman as she undergoes the donation procedure on camera. Because they anticipated a large number of donors during the Super Cure event in 2012, the team at the KTB created the video, titled “What is It Like?”, that walks the viewer through the entire donation process in a step-by-step fashion. The video is available on the KTB website, and based on anecdotal reports from those at the KTB, it has been helpful for potential donors to see the video prior to donation (J. Henry, personal communication February 27, 2014).

Experiences

Finally, it is important to note that the vast majority of donors in the current study indicated that donating was a positive experience in some way, and most had nothing negative to report. Frequent positive experiences included minimal pain and positive treatment by KTB staff and volunteers. Negative experiences were primarily due to the anesthetic and the noise of the

biopsy needle. Thus, the KTB's protocols appear to have succeeded in producing a positive outcome for most donors, despite the unavoidable use of anesthetic and a biopsy needle.

Although the KTB cannot ethically promise "pain-free" surgeries, donor testimonials on other aspects of the experience could form an effective basis for campaign materials (18). In addition, prior donors could be encouraged to talk about their experiences with others, both directly and via social media.

Conclusion

Despite considerable skepticism among members of the scientific and medical community that anyone would choose to donate their healthy breast tissue for research purposes (9), so far, approximately 3,500 women have done just that. The current study contributes to the growing effort to recruit women for the donation of healthy breast tissue. The results of the present study suggest reasons why some women choose to undergo this novel form of medical donation, and offer important clues as to why some women might choose not to donate. Furthermore, this research sheds light on some of the factors that might motivate individuals to give or refuse consent in other biobanking or medical donation contexts. The current study findings clearly indicate the significant role of a breast cancer survivor connection in motivating some women to donate, while also revealing key reasons why young women in particular might be more reluctant to become donors. This study also highlights the important role of personal contact in spreading information about healthy breast tissue donation. With continued research, the recruitment of healthy breast tissue donors can be continued and improved.

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Table 1: Recruiting Media (N = 221)

<i>Media Type</i>	<i>Youth N (%)</i>	<i>Mature N (%)</i>	<i>Total N (%)</i>
Personal contact	23 (34.8)	45 (29.0)	68 (30.8)
Traditional media	3 (4.5)	46 (29.7)	49 (22.2)
Not specified	21 (31.8)	12 (7.7)	33 (14.9)
Electronic media	1 (1.5)	21 (13.5)	22 (10.0)
Presentations and events	13 (19.7)	8 (5.2)	21 (9.5)
E-mail	2 (3.0)	13 (8.4)	15 (6.8)
Flyers	3 (4.5)	10 (6.5)	13 (5.9)

Table 2: Donor Motivations (N = 221)

<i>Motivation Type</i>	<i>Youth N (%)</i>	<i>Mature N (%)</i>	<i>Total N (%)</i>
Cancer survivors, patients, or deaths	28 (42.4)	77 (49.7)	105 (47.5)
Helping the cause	18 (27.3)	26 (16.8)	44 (19.9)
Persuaded to donate by others	8 (12.1)	11 (7.1)	19 (8.6)
Research and advocacy	2 (3.0)	14 (9.0)	16 (7.2)
Future generations	1 (1.5)	5 (3.2)	6 (2.7)
Gratitude or perceived luck (not having cancer)	0 (0.0)	5 (3.2)	5 (2.3)
Is a cancer survivor	0 (0.0)	3 (1.9)	3 (1.4)
Other	9 (13.6)	14 (9.0)	23 (10.4)

Table 3: Donor Concerns (N = 221)

<i>Concern Type</i>	<i>Youth N (%)</i>	<i>Mature N (%)</i>	<i>Total N (%)</i>
None	27 (40.9)	106 (68.4)	133 (60.2)
Pain, discomfort, or weakness	12 (18.2)	24 (15.5)	36 (16.3)
Surgical procedures (needles, blood)	11 (16.7)	6 (3.9)	17 (7.7)
Nervous, anxious, or afraid	9 (13.6)	7 (4.5)	16 (7.2)
Uncertainty	2 (3.0)	5 (3.2)	7 (3.2)
Concerns of others	1 (1.5)	2 (1.3)	3 (1.4)
Other	4 (6.1)	5 (3.2)	9 (4.1)

Table 4: Donor Positive Experiences (N = 135)

<i>Positive Experience Type</i>	<i>Youth N (%)</i>	<i>Mature N (%)</i>	<i>Total N (%)</i>
Minimal pain	6 (9.1)	35 (22.6)	41 (30.4)
Positive KTB staff behavior	11 (16.7)	21 (13.5)	32 (23.7)
Easy/quick	6 (9.1)	13 (8.4)	19 (14.1)
No positive response	3 (4.5)	15 (9.7)	18 (13.3)
Other	5 (7.6)	20 (12.9)	25 (18.5)

Table 5: Donor Negative Experiences (N = 135)

<i>Concern Type</i>	<i>Youth N (%)</i>	<i>Mature N (%)</i>	<i>Total N (%)</i>
No negative response	15 (48.4)	73 (70.2)	88 (65.2)
Anesthetic shot	6 (19.4)	10 (9.6)	16 (11.9)
Biopsy machine (needle, noise)	2 (6.5)	8 (7.7)	10 (7.4)
Blood drawn	1 (3.2)	1 (1.0)	2 (1.5)
Other	7 (22.6)	12 (11.5)	19 (14.1)