CLINICAL TRIAL

The decision-making experience among women diagnosed with stage I and II breast cancer

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Abstract A cancer diagnosis signals entry for many patients into the complex and often bewildering world of cancer care. Understanding the role women prefer and their level of satisfaction with the decision-making process at time of diagnosis will help to inform healthcare professionals how to better support breast cancer patients as they navigate the cancer journey. Logistic regression was used to identify significant factors influencing outcomes in role preferences and satisfaction. A complementary method, principal components analysis was used to explore patterns of co-association between outcomes and their influencing factors. Results showed women tended to adopt cancer decision-making roles similar to those used for general health decision-making. Overall, women preferred a collaborative/active role (40/38%) over a passive role (16%). Satisfaction rates were high with 88.1% of women being satisfied/very satisfied with their cancer treatment choice; 89.7% of women satisfied with their decision-making role and; 83.6% satisfied with the information provided to support their decision. Further

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D. Rayson Cancer Care Program, Capital District Health Authority, Halifax, Canada research involving cohorts of women diagnosed with more advanced disease and for whom decisional regret may be greater, is needed to further explore the link between preferred decision-making role and satisfaction.

Keywords Breast cancer · Cancer care · Decisionmaking · Decision satisfaction · Information satisfaction · Role preference

Introduction

A diagnosis of cancer signals entry into a complex and often bewildering medical care pathway comprised of multiple layers of services and a myriad of healthcare professionals providing these services. Complexity is substantial and arises at a time when individuals are engaging in difficult decision-making processes surrounding their care. The expected level of patientinvolvement in selecting a treatment modality as well as the expanding array of available treatments may augment this complexity and lead to difficulties in integrating information and decision-making. Individuals may feel overwhelmed, anxious, pressured, and receive conflicting or insufficient information which may affect comfort with the decision-making process at critical junctures in care leading to the potential for decision-regret or dissatisfaction with chosen therapies.

Treatment choices are not the sole result of rational evaluation but are influenced by situational, interpersonal and individual determinants (Fallowfield 1997; Siminoff et al. 1989). With more women surviving breast cancer, growing public education initiatives, greater access to information about the disease and treatment options, and women's health and consumer rights movements, a greater accountability for personal health and involvement in medical decisions has developed (Petrisek et al. 1997).

Conflicting results have been reported in studies examining patient preferences in decision-making regarding breast cancer therapy. Cancer patients may follow one of several paths of action in relation to decision-making such as leaving the treatment decision to their physicians (Degner et al. 1997; Degner and Sloan 1992; Fallowfield 1997; Johnson et al. 1996; Petrisek et al. 1997), to taking a more active role (Blanchard et al. 1988; Cassileth et al. 1980; Mastaglia and Kristjanson, 2001; Sainio et al. 2001). Shared decision-making, where decision about treatment arises from a mutual negotiation between the patient and the physician has been observed to be most preferred by patients (Braddock et al. 1999; Bruera et al. 2002; Deber et al. 1996; Keating et al. 2002; Schou et al. 2002).

Decision-regret or dissatisfaction arises out of uncertainty around actions. "Regrets may arise when making choices that involve risk or uncertainty of outcomes; high stakes in terms of potential gains and losses" (O'Connor 1995, p. 25). Hypothesized factors contributing to decisional regret include lack of information around alternatives, poor decision-making skills, perceived pressures from individuals in positions of authority (i.e., physician/surgeon or other health professionals), and emotional distress (Balneaves and Long 1999; Degner and Sloan 1992; O'Connor 1995; Petrisek et al. 1997; Siminoff et al. 1989). Women making decisions for breast cancer treatment have described the process as "most stressful due to uncertainty and ambiguity about the disease, insufficient information, and the immediate need to make treatment decisions" (Balneaves and Long 1999, p. 1322).

Patients diagnosed with early stage breast cancer (stage I or II) are commonly offered either breast conserving surgery (BCS-lumpectomy) or mastectomy with essentially equivalent outcomes (Scarth et al. 2002). Additionally, based on final pathology results after surgery, patients are commonly offered a variety of potential adjuvant hormonal, chemo- and radiation-therapies. The role of patients in selecting treatment modalities (both surgical and non-surgical) and the level of satisfaction that ensues have yet to be explored. This study: (1) examines how women perceive their role in the decision-making process at the time of a breast cancer diagnosis; (2) assesses the level of satisfaction experienced by women with regard to the decision they made about their cancer treatment, the role they adopted in making that decision and the amount/type of information they received, and; (3) explores determinants of role decision preference and decision satisfaction

Methodology

Women diagnosed with invasive breast cancer between January 1st 2000 and December 31st 2003 were identified from the Oncology Patient Information System (OPIS) maintained by the Nova Scotia Cancer Registry. Patients aged 18 and older, diagnosed in Nova Scotia with a pathologically confirmed stage I or II disease, and for whom their last day of adjuvant therapy was prior to March 15th 2003 met the inclusion criteria for the study. Cases with in situ disease (ductal or lobular) were excluded, as were those with any prior invasive cancer diagnosis.

Approval was received from Capital District Health Authority Ethics Review Board to send a mail-out survey to all women meeting the study inclusion criteria. A subset of women volunteered to participate in telephone interviews and focus groups. This comprehensive retrospective mixed method approach was adopted to improve our understanding of women's role in decision-making processes at diagnosis. Perceived satisfaction level about their role in the treatment choice, decision made or information received was also examined. The following discussion will focus on the survey component of the study.

For confidentiality purposes, the subject contact process was managed by the Nova Scotia Cancer Registry. A comprehensive package, including study information, survey and interview consent form was mailed to the 1,117 eligible women, between January and February 2004. A total of 611 (55%) surveys were completed and used for analysis. The survey contained two parts; the first collected demographic information, familial and personal cancer history, and cancer treatment details (e.g., type of surgery, adjuvant treatment, etc.); the second, targeted questions regarding: (1) role preferences in decision-making for typical health choices (Health Decision Role Preference); (2) role preference in decision-making regarding their breast cancer treatment (Cancer Decision Role Preference); (3) overall satisfaction with their breast cancer treatment decisions (Decision Satisfaction); (4) satisfaction with their role in the cancer decision-making process (Role Satisfaction) and; (5) satisfaction with the amount and type of breast cancer information they received (Information Satisfaction).

An ordinal role preference scale from Degner and Sloan (1992) was used to rank both the *Health and* *Cancer Decision Role Preference* questions (Fig. 1, reproduced with permission from Degner 1992). A 4-point Likert scale was used to rank *Decision Satisfaction* from: not satisfied, somewhat satisfied, satisfied to very satisfied. A "yes/no" binary response was used to target *Role Satisfaction* and *Information Satisfaction*. The overall survey was based on a questionnaire developed by Degner and Sloan (1992).

Logistic regression analysis with stepwise selection (P < 0.05) was used to identify the dominant factors influencing outcomes in role preference and satisfaction level. These factors included: age of the woman at diagnosis (Age); area of residence (Residence); ethnic background (Ethnicity); education level (Education); total income (Income); marital status (Status); number of children (Children); pregnancy in the last 5 years (Pregnancy); history of having breast fed (Breast Fed); expectation of a cancer diagnosis (Diagnosis Expectation); friend/colleague with a history of breast cancer (Friend History); family history of breast cancer (Family History); history of breast problems (Breast Problems); previous invasive cancers (Previous Cancer); disease stage at diagnosis (Stage); time since diagnosis (Time Since Diagnosis); number of information providers (Information Providers); type of surgery (Surgery); and whether the women had received hormonal therapy (Hormonal Therapy-Hx, chemotherapy (Chemotherapy-Cx) and or radiotherapy (Radiotherapy—Rx).

A principal component analysis (PCA) was used to explore the simultaneous correlations amongst all variables of interest (i.e., decision role preferences, decision/role/information satisfaction and all



Fig. 1 Ordinal role preference scale (Degner and Sloan 1992)

influencing factors). PCA is a multivariate method (Manly 1986; Legendre and Legendre 1998; Smith 2002) that decomposes the correlations or co-variances between all variables into subsets that best captures the total variability in the data. These subsets are new composite variables ("principal axes" e.g., PC1, PC2, etc.) holding information from all variables of interest but largely reflecting those variables with the greatest variability and therefore the strongest influence (thus the name "principal component"). Dominant patterns in a dataset can usually be summarized by the first two or three "principal component axes" (PC1, PC2, PC3), with the primary axis (PC1) accounting for the greatest proportion of the variation in the dataset; the second axis (PC2) accounting for the next largest variations etc. Two PCs were used (PC1 and PC2) in this analysis. The graphical presentation of these composite axes (known as an "ordination") has the feature that women sharing similar characteristics will tend to cluster together. In this study, correlations amongst women are determined based upon their profiles (demography, familial, cancer and treatment history, etc.) their role preference and satisfaction. Women with "common" profiles or experiencing "average" role preference or satisfaction will usually cluster near the centre of the ordination whereas women with atypical profiles or adopting atypical role preference (either very active or passive) or experiencing atypical satisfaction (e.g., either very satisfied or not satisfied at all) will cluster further away from the centre towards the extremes of the data distribution.

Results

A total of 611 out of 1,117 women responded to the mailed-out survey, resulting in a 55% response rate. Demographic information, family/friends/cancers history, and cancer treatment details (type of surgery, adjuvant treatment, etc.) of participants are summarized in Table 1 Respondents were largely Caucasians, aged 50–69 years and married with children. Most of these women had never experienced a cancer diagnosis (91.8%) and had not expected one (64.7%). Post diagnosis, 60% of these women opted for mastectomy as surgical treatment and 54% had been diagnosed at least 2 years prior to study entry.

A significant association was observed between *Health Decision Role preference* and *Cancer Decision Role preference* (P < 0.0001; Table 2, indicating that women adopted similar role preferences when making a decision relating to either their general health or their breast cancer treatment. As suggested by earlier

Table 1 Profileofcharacteristics for participants

Factor	Number of women (%)	Factor	Number of women (%)	
Residence		Seeking advice		
Urban	246 (43.6)	No	117 (19.2)	
Rural	318 (56.4)	Yes	332 (54.3)	
Age		Friend with history of brea	st ca.	
18–49	157 (25.7)	No	328 (53.7)	
50-69	346 (56.6)	Yes	278 (45.5)	
≥70	89 (14.6)		()	
		Family with history of brea	breast ca.	
Ethnicity		No	387 (63.3)	
Caucasian	498 (81.5)	Yes	219 (35.8)	
Other	99 (16.2)			
		Breast problems history		
Education		No	407 (66.6)	
Elementary	27 (4.4)	Yes	200 (32.7)	
Junior high	71 (11.6)			
High school	215 (35.2)	Stage		
Community college	166 (27.2)	I	229 (37.5)	
Undergraduate	39 (6.4)	IIa	149 (24.4)	
Graduate	75 (12.3)	IIb	75 (12.3)	
Income		Time since diagnosis		
<20 K	115 (18.8)	0–12 months	22 (3.6)	
21–39 K	143 (23.4)	13–18 months	107 (17.5)	
40–59 K	116 (19.0)	19–24 months	140 (22.9)	
60–80 K	108 (17.7)	25+ months	327 (53.5)	
Status		Information providers		
Single	190 (31.1)	0	45 (7.4)	
Married	407 (66.6)	1	322 (52.7)	
		2	157 (25.7)	
		>3	87 (14.2)	
Children				
None	72 (11.8)	Surgery		
1–2	293 (48.0)	Lumpectomy	239 (39.1)	
>3	242 (39.6)	Mastectomy	369 (60.4)	
Pregnancy		Hormonal therapy (Hx)	()	
No	604 (98.9)	No	237 (38.8)	
Yes	6 (1.0)	Yes	367 (60.1)	
Breast feeding history		Chemotherapy (Cx)		
No	393 (64.3)	No	379 (62.0)	
Yes	216 (35.4)	Yes	226 (37.0)	
Diagnosis expectation		Radiotherapy (Rx)		
No	395 (64.7)	No	337 (55.2)	
Yes	198 (32.4)	Yes	274 (44.8)	

researchers (Braddock et al. 1999; Bruera et al. 2002; Deber et al. 1996; Keating et al. 2002; Schou et al. 2002), participants largely favoured a collaborative/ active role over a passive one (*Health Decision Role preference*: 40/38% vs. 16%; *Cancer Decision Role preference*: 24/47% vs. 22%; Table 2. Total income was

Table 2 Decision role preference for health decision and cancer treatment decision

Decision role pre	ference ^a	General health decision	Cancer treatment decision	
Active	Patient selects treatment Patient select treatment considering doctor's opinion	Number of women 199 (32.6) 35 (5.7)	203 (33.2) 84 (13.7)	
Collaborative Passive	Doctor and patient share responsibility for treatment selection Doctor select treatment considering patient's opinion Doctor selects treatment	242 (39.6) 48 (7.9) 49 (8.0)	148 (24.2) 87 (14.2) 45 (7.4)	

^aA significant association was observed between *Health Decision Role preference* and *Cancer Decision Role preference* ($X^2 = 321.9$, P < 0.001)

the most important factor associated with *Health* Decision Role preference: women with higher income were twice as likely to adopt an active role in decisionmaking compared to women with an income under 20,000 dollars per year (40-59 K: OR 2.1, 95% CI 1.3-3.5, P = 0.003; 60–90+ K: OR 1.9, 95% CI 1.2–3.2, P = 0.012; see Table 3). The likelihood (OR) of being actively involved in selecting a cancer treatment (Cancer Decision Role Preference) was associated with the level of completed education and bias to seek advice for significant decisions. Women with graduate education were four times as likely to adopt an active role in decision-making compared to women with elementary school education (Graduate: OR 4.4, 95% 1.8–11.1, P = 0.002; Table 3); those seeking advice were twice as likely to be active compared to women not seeking advice (Seeking advice: OR 2.4, 95% CI 1.6-3.5, P < 0.0001; Table 3).

A high satisfaction rate was observed amongst respondents, with 88.1% of women being satisfied/very satisfied with their cancer treatment choice; 89.7% of women satisfied with their role played in making decisions about their treatment and; 83.6% satisfied with the amount/type of information provided to support decision-making (Table 4). *Decision Satisfaction* about treatment was significantly associated with the

Table 3 Significant predictors of measured outcomes derived from ordinal logistic regression analysis

Role preference ^a	Ν	OR ^b	95% CI ^c	P-value ^d
Health decision				
Total income				
<20 K*	102	1	_	_
21–39 K	135	0.9	(0.57 - 1.5)	0.732
40–59 K	114	2.1	(1.3–3.5)	0.003
60–80+ K	108	1.9	(1.2 - 3.2)	0.012
Cancer decision ^e				
Education				
Elementary*	19	1	_	_
Junior high	63	2.3	(0.91 - 5.8)	0.080
High school	202	1.6	(0.67 - 3.6)	0.308
Community college	158	2.2	(0.92 - 5.1)	0.078
Undergraduate	37	2.4	(0.87 - 6.4)	0.090
Graduate	72	4.4	(1.8 - 11.1)	0.002
Seek advice			. ,	
No*	110	1	_	_
Yes	315	2.4	(1.6 - 3.5)	< 0.0001

* Reference group

^a Model adequately predicts 61% of the response measure

^b Odds ratio (OR)

^c OR 95% confidence intervals

^d *P*-value derived from an adjusted ordinal logistic regression model

^e Model adequately predicts 56% of the response measure

Table 4 Satisfaction rates	Table 4	Satisfaction	rates
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Satisfaction	Number of women (%)			
Decision satisfaction				
Not satisfied	10 (1.6)			
Somewhat satisfied	19 (3.1)			
Satisfied	141 (23.1)			
Very satisfied	397 (65.0)			
Role satisfaction	~ /			
Not satisfied	33 (5.4)			
Satisfied	548 (89.7)			
Information satisfaction	· · · · ·			
Not satisfied	61 (10.0)			
Satisfied	511 (83.6)			

number of 'helpful' information providers: women receiving information from three or more providers were twice as likely to be satisfied with their cancer treatment choice compared to women receiving information from one provider (3+ providers: OR 2.2, 95% CI 1.2–4.0, P = 0.01; Table 5). Factors contributing to *Role Satisfaction* included the age of the patient at diagnosis and whether the patient expected a cancer diagnosis. Women's satisfaction increased 50% for every 10 years of age gained; and those women expecting a cancer diagnosis were three times as likely to be satisfied with their role in cancer treatment

 Table 5 Significant predictors of measured outcomes derived from ordinal logistic regression analysis

Satisfaction	Ν	OR^b	95% CI ^c	P-value ^d
Decision satisfaction ^a				
Number of information providers				
1*	312	1	_	_
2	149	1.4	(0.92 - 2.2)	0.123
3+	85	2.2	(1.2–4.0)	0.01
Role satisfaction ^e			· /	
Age (decades)	581	1.51	(1.08 - 2.1)	0.016
Diagnosis expectation			. ,	
No*	375	1	_	_
Yes	190	3.4	(1.2 - 9.9)	0.024
Information satisfaction ^f			· /	
Age	151	1	_	_
18–49				
50-69	326	2.3	(1.4 - 4.1)	0.003
≥70*	76	17.8	(2.4–133.6)	0.005

* Reference group

^a Model adequately predicts 37% of the response measure

^b Odds ratio (OR)

^c OR 95% confidence intervals

^d *P*-value derived from an adjusted ordinal logistic regression model

^e Model adequately predicts 69% of the response measure. Age groups not used due to convergence failure

^f Model adequately predicts 45% of the response measure

decision-making as compared to women not expecting a cancer diagnosis (Age (decades): OR 1.5, 95% CI 1.1–2.1, P < 0.016; Diagnosis Expectation: OR 3.4, 95% CI 1.2–9.9, P < 0.024; Table 5). The age of the patient at diagnosis was also significantly associated with the level of satisfaction reported with the amount/ type of breast cancer information received (*Information Satisfaction*): women aged 50–69 were twice as likely to be satisfied compared to women aged 18–49; those aged 70 and older were nearly 18 times more likely to be satisfied compared to the youngest age group (age 50–69: OR 2.3, 95% CI 1.4–4.1, P < 0.003; age 70+: OR 17.8, 95% CI 2.4–133.6, P < 0.005; Table 5).

No relationship was observed between Health Decision Role Preference and Decision Satisfaction (P = 0.531; Table 6) nor between *Health Decision Role* Preference and Role Satisfaction (P = 0.102) nor between Cancer Decision Role Preference and Role Sat*isfaction*: P = 0.126; Table 6). However, women adopting an active role in decision-making about their cancer treatment were generally more satisfied than those that were less active (Cancer Decision Role *Preference* × Decision Satisfaction: P = 0.046; Table 6). Women adopting an active role in decisionmaking about their general health or breast cancer treatment were less satisfied with the type/amount of information they received, while those adopting a collaborative role were observed to be more satisfied (Health Decision Role Preference × Information Satisfaction: P = 0.001; Cancer Decision Role Preference \times Information Satisfaction: P = 0.009; Table 6).

The most important patterns of co-associations amongst all variables of interest are summarized in the ordination presented in Fig. 2. In this study, the "principal axis" (PC1 accounting for 11% of the total variance in the data) largely reflects the *Role prefer*ence in decision-making, the women' age at diagnosis, their marital status, education and income levels. PC1 shows that younger women, married, with higher education and income levels tend to adopt an active role in decision-making; whereas older women, single (single/divorced/separated/widowed), with lower education and income levels largely adopt a passive role in decision-making (Fig. 2). The next most important "principal axis" (PC2, accounting for 8% of the total variance in the data) largely reflects the level of perceived Satisfaction, disease stage, presence of friend with a history of cancer, bias to seek input for significant decision and access to multiple information providers to support cancer decision. PC2 demonstrates that women diagnosed at an early disease stage, with a friend's history of breast cancer, typically seeking input and receiving information from a large number of providers tended to express high levels of satisfaction with the decision they made about their cancer treatment, the role they adopted while making that decision and the amount/type of information they received. In contrast, women diagnosed at a more advanced disease stage, with no friend's history of breast cancer, not seeking input and receiving information from a smaller number of providers expressed high levels of dissatisfaction with their role played in treatment choice, decision made or information received.

Patterns of co-associations can be further explored by focusing upon specific quadrants (Q1, Q2, Q3, Q4) of the ordination which reflect the combined influence of those variables influencing PC1 and PC2. For example, women clustering in Q1 generally diagnosed with stage I disease, with a friend's history of breast cancer, seeking inputs, receiving information from a large number of providers, older in age, single, with

Table 6 Contingency χ^2 -test showing associations between *role preference* and satisfaction

Role preference	Satisfaction								
	Decision satisfaction				Role satisfaction		Information satisfaction		
	Not satisfied	Somewhat satisfied	Satisfied	Very satisfied	Not satisfied	Satisfied	Not satisfied	Satisfied	
Health decision									
Active	5 (2.2)	10 (4.4)	48 (21.3)	162 (72.0)	17 (7.4)	213 (92.6)	39 (17.0)	190 (83.0)	
Collaborative	3 (1.4)	7 (3.1)	58 (26.0)	155 (69.5)	15 (6.4)	218 (93.6)	17 (7.5)	211 (92.5)	
Passive	2(2.2)	1 (1.1)	27 (29.7)	61 (67.0)	1 (1.1)	87 (15.8)	5 (5.8)	82 (94.3)	
γ^2 -test:	γ^2 5.1. <i>P</i> -value 0.531		χ^{2} 4.6, <i>P</i> -value 0.102		χ^2 13.6, <i>P</i> -value 0.001				
Cancer decision									
Active	2 (0.73)	13 (4.8)	59 (21.6)	199 (72.9)	14 (5.0)	267 (95.0)	38 (13.8)	237 (86.2)	
Collaborative	2 (1.4)	2 (1.4)	39 (27.7)	98 (69.5)	4 (2.8)	141 (97.2)	6 (4.2)	138 (95.8)	
Passive	5 (4.1)	2 (1.6)	34 (27.9)	81 (66.4)	10 (8.3)	111 (91.7)	14 (11.4)	109 (88.6)	
χ^2 -test:	χ^2 12.8, <i>P</i> -value 0.046			χ^2 4.1, <i>P</i> -value 0.126		χ^2 9.3, <i>P</i> -value 0.01			



Fig. 2 Ordination showing the inter-relationships between outcomes (<- Health/Cancer Role Preferences, Decision/Role/Information Satisfaction Levels) and their influencing factors (<--). Longer arrows indicate stronger influences. Arrows

pointing in the same directions indicate strong co-associations. Cases (women) appear as points. Arrows for categorical responses or cofactors point in the direction of the highest classification order as described in Table 1

lower education and income levels, tended to adopt a more passive role preference and expressed high levels of satisfaction. In contrast, women clustering in Q3 generally diagnosed with stage II disease, without a friend's history of breast cancer, not seeking inputs, receiving information from a limited number of providers, younger, married with higher education and income levels, tended to adopt a more active role preference and expressed low levels of satisfaction. Women clustering in Q2 were active and satisfied; those clustering in Q4 were passive and unsatisfied. Stronger associations were observed between Health/ Cancer Decision Role Preferences and the measured influencing factors than were observed between Decision/Role/Information Satisfaction and those same factors.

Discussion

The majority of study participants diagnosed with early breast cancer (stage I or II) in Nova Scotia opted for a collaborative (39.6%)/active (38.3%) role in making decisions surrounding their treatment. These results are consistent with those in the literature and highlight the increased popularity of a *shared-decision-making model* in which decisions about treatment arise as a direct result of mutual negotiation between the patient and physician and not exclusively from the physician's own opinion. Participants opting for a more passive role in decision-making about their cancer treatment care were fewer (15.9%) and largely comprised women from an older age group (>70 years old) for which the traditional *paternalistic-decision-making model* in which the physician exclusively selects the treatment of choice might be more familiar and/or consistent with their beliefs.

Decision-regret or dissatisfaction amongst respondents was negligible, with approximately 5% of women expressing dissatisfaction about their treatment decision or the role they played in making their decision; and 10% expressing dissatisfaction about the type and amount of information they received to support their decision-making. While these findings are reassuring for the health care providers they are limiting from an analytical perspective. Analyses exploring determinants of decision-regret require a pool of respondents representing a broad experience of decision satisfaction to reasonably detect determinants and generalize results. A high satisfaction rate amongst respondents may also reflect two types of selection bias in which: (1) patients highly satisfied with their overall experience in decisionmaking may be more inclined to participate in a survey than patients that have experienced treatment decisionregret or dissatisfaction with their role or support; (2) patients diagnosed with early breast cancer (stages I, II) may have a better prognosis relative to patients diagnosed at a more advanced disease stage and as a result may experience higher level of satisfaction due to more positive outcomes.

The study suggests that women diagnosed at an early disease stage (stage I), having a friend with a history of breast cancer, who seek input for significant decisions, as well as receiving information from a large number of providers tend to adopt an active role in cancer treatment decision-making and express high levels of satisfaction with their cancer treatment-decision, the role they adopted while making that decision and the amount/type of information they received. Previous exposure to a family or friend with a good outcome after a breast cancer diagnosis may lead to increased hope and provide relevant information resulting in a 'lead-time bias' through familiarity with the disease, treatment options and needed resource supports which may, in turn influence overall decisionmaking satisfaction.

Women who accessed three or more information providers were 2.2 times more likely to be satisfied with their decision-making than women who accessed fewer information providers (Table 5). Seeking additional information or second opinions may be suggestive of active involvement in decision-making (Mellink et al. 2003). A review of the 1992 National Health Interview Survey identified seeking multiple sources of information and/or second opinions as more likely to occur in women with breast cancer because of different treatment options with comparable outcomes as well as heightened awareness of different treatment options due to extensive media coverage (Hewitt et al. 1999). The use of multiple information providers may afford women an opportunity to evaluate their options, give them 'breathing space' or time to internalize the information, increase confidence around choice, and ensure consistency and/or continuity of their care. This finding also begs the question of the relative importance of who the information providers are versus how the information is obtained.

Given the lack of an observed relationship between preferred *Cancer Decision Role* and *Role Satisfaction*

more research is needed to identify the variables influencing the relationship between preferred decision-making roles and satisfaction. The lack of relationship may be due, in part, to the focus on early stage rather than advanced stage breast cancer. A comparison of both groups (early and advanced) may help to shed light on the drivers behind decision satisfaction and regret by highlighting variables such as uncertainty of outcome, control, time, and anticipation of positive diagnosis. Further, the study could benefit by taking a longitudinal rather than retrospective approach. Following women over time may assist in determining the sustainability of satisfaction with decisions and roles. Finally, the use of a qualitative methodology which speaks to issues raised during the interview component of this study, as well as the introduction of more in depth questions about the interview process may prove beneficial by bringing to light the experience of decision-making at time of diagnosis.

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References

- Balneaves LG, Long B (1999) An embedded decisional model of stress and coping: implications for exploring treatment decision making by women with breast cancer. J Adv Nurs 30(6):1321–1331
- Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB (1988) Information decision-making preferences of hospitalized adult cancer patients. Soc Sci Med 27(11):1139–1145
- Braddock CH III, Edwards KA, Hasenberg NM, Laidley TL, Levinson W (1999) Informed decision making in outpatient practice: time to get back to basics. JAMA 282(24):2313– 2320
- Bruera E, Willey JS, Palmer JL, Rosales M (2002) Treatment decisions for breast carcinoma: patient preferences and physician perceptions. Cancer 94(7):2076–2080
- Cassileth BR, Heiberger RM, March V, Sutton-Smith K (1980) Information seeking and participation preferences among cancer patients. Ann Intern Med 92(6):832–836
- Deber RB, Kraetschmer N, Irvine J (1996) What role do patients wish to play in treatment decision making? Arch Intern Med 156:1414–1420
- Degner LF, Sloan JA (1992) Decision-making during serious illness: what role do patients really want to play? J Clin Epidemiol 45(9):941–950
- Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, Bilodeau B, Watson P, Mueller B (1997) Information needs and decisional preferences in women with breast cancer. JAMA 277(18):1485–1492
- Fallowfield L (1997) Offering choice of surgical treatments to women with breast cancer. Patient Educ Couns 30(3):209– 214

- Hewitt M, Breen N, Devesa S (1999) Cancer prevalence and survivorship issues. Analyses of the 1992 National health Interview Survey. J Natl Cancer Inst 91:1480–1486
- Johnson JD, Roberts CS, Cox CE, Rientgen DS, Levine JS, Parsons M (1996) Breast cancer patients' personality style, age and treatment decision-making. J Surg Oncol 63(3):183–186
- Keating NL, Guadagnoli E, Landrum MB, Borbas C, Weeks JC (2002) Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? J Clin Oncol 20(6):1473–1479
- Legendre P, Legendre L (1998) Numerical ecology. Amsterdam, Elsevier
- Manly B (1986) Multivariate statistical methods: a primer. Chapman and Hall, New York
- Mastaglia B, Kristjanson LJ (2001) Factors influencing women's decisions for choice of surgery for Stage I and Stage II breast cancer in Western Australia. J Adv Nurs 35(6):836–847
- Mellink WAM, Dulmen AM, Wiggens T, Spreeuwenberg PMM, Eggermont AMM, Bensing JM (2003) Cancer patients seeking a second surgical opinion: results of a study on motives, needs and expectations. J Clin Oncol 21:1492–1497

- O'Connor AM (1995) Validation of a decisional conflict scale. Med Decis Making 15(1):25–30
- Petrisek AC, Laliberte LL, Allen SM, Mor V (1997) The treatment decision-making process: age differences in a sample of women recently diagnosed with non-recurrent early stage breast cancer. Gerontologist 37(5):598–608
- Sainio C, Eriksson E, Lauri S (2001) Patient participation in decision-making about care. Cancer Nurs 24(3):172–179
- Scarth H, Cantin J, Levine M (2002) Clinical practice guidelines for the care and treatment of breast cancer: mastectomy or lumpectomy? The choice of operation for clinical stages I & II breast cancer (summary of the 2002 update). CMAJ 167(2):154–155
- Schou I, Ekeberg O, Ruland CM, Karesen R (2002) Do women newly diagnosed with breast cancer and consulting surgeon asses decision-making equally? Breast 11(5):434–441
- Siminoff LA, Fetting JH, Abeloff MD (1989) Doctor-patient communication about breast cancer adjuvant therapy. J Clin Oncol 7(9):1192–1200
- Smith L (2002) A tutorial on principal components analysis