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Receiving/declining adjuvant breast cancer treatments and involvement in treatment decision-making☆

Eunjung Kim[a,*], M. Robyn Andersen[b], Leanna J. Standish[c]

[a] Department of Family and Child Nursing, University of Washington, United States
[b] Translational Sciences Program, Fred Hutchinson Cancer Research Center, United States
[c] School of Naturopathic Medicine, Bastyr University, United States

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ABSTRACT

Objectives: This study compared women who received all recommended breast cancer treatments (Receivers) with those who did not (Decliners). We sought to understand women's integrative naturopathic oncology (INO) use in addition to usual conventional oncology (UCO) use, their involvement in treatment decision-making (TDM), and their satisfaction with healthcare providers.

Methods: A secondary analysis was conducted using baseline data from the Breast Cancer Integrative Oncology Study that recruited 427 women from INO clinics (INO cohort) and comparison women from the Cancer Surveillance System Registry who received UCO care (UCO cohort) in Western Washington State. Self-reported data and Registry data were analyzed using descriptive statistics, t-tests, and X2 tests to compare Receivers and Decliners in demographic and disease characteristics, use of INO in addition to UCO care, involvement in TDM, and satisfaction with healthcare providers.

Results: Significantly more Decliners were in INO cohort than UCO cohort. Decliners in INO cohort were less likely to receive radiotherapy. Women who used INO care, and Decliners, compared with Receivers, tended to be "very involved" in their TDM. No difference was found in participation congruence, correspondence between preferred and actual involvement in medical TDM, between groups. Decliners in INO cohort reported significantly less satisfaction with their conventional oncologist than Receivers in INO cohort.

Conclusions: Decliners of conventional adjuvant therapies were very involved in their TDM and those Decliners who seek INO care were less satisfied with their conventional oncologist; these women may need the most attention to assure they receive the care they need.

1. Introduction

Over three million women have breast cancer in the U.S., comprising 41% of all female cancer survivors in 2014.[1] An estimated 330,080 women were newly diagnosed with breast cancer in the United States in 2018, and this number has been increasing each year (American Cancer Society, 2018). Approximately 6–11% of these women would voluntarily decline recommended chemotherapy[2–4]; 9% radiotherapy,[5] and 14% hormone therapy.[6] However, not much is known about women's involvement in making these important treatment choices, declining conventional treatment and choosing complementary and alternative medicine, and whether there are differences in involvement in treatment decision-making (TDM) between women who receive (i.e., *Receivers*) and don't receive (i.e., *Decliners*) all recommended conventional treatments.

What we know about the demographic and clinical characteristics of women who decline conventional treatments is that they tend to be older, less educated, single women who often live alone, and have disabilities that hinder their activities of daily living.[3,4,7] Decliners also have clinical predictors of good outcomes, such as smaller tumor size, negative nodes, lower grade, and positive estrogen and progesterone receptor status. In addition, Decliners were more likely to perceive their conventional oncologist as uncaring, insensitive, and unnecessarily harsh.[8,9] When these women make decision, they seemed to evaluate

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* Corresponding author at: Department of Family and Child Nursing, University of Washington, Box 357262, Seattle, WA 98195, United States.
E-mail address: eunjungk@uw.edu (E. Kim).

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the burden of treatments (i.e., length of the hospital stay, length of the treatment, extent of testing, invasiveness of intervention, and side effects) and treatment outcomes such as quality of life, rate of survival with and without treatments.[9–11]

We also know that western women with breast cancer generally prefer to be involved in TDM. In a study conducted in Western Washington, 72% of women with breast cancer reported that they were very involved in TDM regarding their overall treatment, followed by 23% reporting some involvement, and only 5% reporting no involvement.[12] This rate is much higher than what was found in a meta-analysis of 6 studies that examined involvement in TDM in North America; that study found 36% of individuals with cancer had passive role, followed by 34% shared role, and 30% active role.[13] This difference probably is related to different way of conceptualization of patient involvement (e.g., assessing the level of involvement vs. shared decision making). Among Chinese-Australian women with breast cancer, TDM of women with breast cancer was influenced by language barriers and culturally rooted expectations on the role of doctors and families; only 17% of women played an active role, whereas 43% reported a passive decision-maker role, and an additional 39% of women were a reluctant or reluctant passive decision maker(,[14 15]).

In addition, not all women will achieve the level of involvement they would prefer. Meta-analyses have found that about 60–61% of individuals reported participation congruence, correspondence between preferred and actual involvement in TDM in medical treatments, with most reporting wishing for more involvement than they achieved.[13,16] This rate is lower than 80% of participation congruence found among Chinese women with breast cancer living in Hong Kong.[17]

About 80% of women with breast cancer, both Receivers and Decliners, seek complementary and alternative medicine.[4,8,10,18] However, only a smaller percentage of women seek care from integrative oncology doctors, who represent an emerging field that multidisplinary providers such as naturopathic doctors, traditional Chinese medical doctors, and conventional physicians with additional training in complementary medicine, and who seek to improve health outcomes of individuals affected by cancer. Integrative oncology care providers address individual's physical, psychological, and spiritual needs during and after usual conventional oncology (UCO) care.[19,20] This may be especially true of naturopathic doctors who are board certified in naturopathic oncology (Fellows of the American Board of Naturopathic Oncology) who seek to provide patient-centered, evidence-based cancer treatments such as nutrition, botanical medicine, mind and body therapy, and lifestyle changes that can be used in conjunction with conventional treatments.[20,21] But, little is known about women, both Receivers and Decliners, who seek integrative naturopathic oncology (INO) care, and their involvement in TDM or their satisfaction with healthcare providers.

The goal of this study was to compare women who received all recommended conventional breast cancer treatments (Receivers) with those who did not (Decliners); we sought to understand the role of INO care use, involvement in TDM, and women's satisfaction with healthcare providers. The specific objectives were 1) to estimate rates of Receivers and Decliners among women with breast cancer who did and did not use INO care and 2) to compare involvement in TDM and satisfaction with healthcare providers between Receivers and Decliners among women with breast cancer who did and did not receive INO care.

2. Methods

2.1. Study population

This secondary analysis used the enrollment data from the Breast Cancer Integrative Oncology Study. That study examined health-related quality of life and clinical outcomes associated with women with breast cancer who received INO care in addition to UCO care (i.e., INO cohort), compared with women who received only UCO care (i.e., UCO cohort). In the original study, the self-report data were collected from 585 women from 2009 to 2016. INO cohort women met these criteria: 1) 18 years of age or older, 2) biopsy pathology verified diagnosis of breast cancer or ductal carcinoma in situ, 3) two or more appointments within 4 months with a participating INO physician at one of the six INO clinics in the Western Washington State, and 4) initial diagnosis within two years prior to presentation for INO clinic care. After recruiting women for the INO cohort, women in the comparison UCO cohort were recruited based on similarity (i.e., age and stage at diagnosis, ethnicity, marital status, and estrogen and progesterone receptor status) between women in the INO and UCO cohorts using the Cancer Surveillance System (CSS) registry in Western Washington State.[22]

Among the original sample of 585 women, 427 women (155 in the INO cohort which included 131 Receivers and 24 Decliners; and 272 in the UCO cohort which included 248 Receivers and 24 Decliners) had medical records clearly indicating both an appropriate surgery, and receipt of a medical recommendations for at least one adjuvant treatment (i.e., chemotherapy, radiotherapy, or hormone therapy), and documentation of receipt/non-receipt of that treatment. Power analysis for the continuous variables shows 83% and 86% power to detect difference between cohorts of 0.65 standard deviations (Cohen's d = .65) within the INO and UCO cohort, respectively. Power analysis for the binary variable of the INO cohort shows 88% power to detect a difference between cohorts of 45% vs. 80% with the sample size of 131 vs. 24. Power analysis for the binary variable of the UCO cohort shows 91% power to detect a difference between cohorts of 45% vs. 80% with the sample size of 248 vs. 24.

2.2. Instruments

Data sources included participants' self-reports recorded in a survey conducted on study enrollment and medical record data collected from the Cancer Surveillance System (CSS) registry in Western Washington State. Self-reported items included household income, comorbidity, involvement in TDM, and satisfaction with healthcare providers. CSS data included age and stage at diagnosis, ethnicity, marital status, estrogen and progesterone receptors status, and side of breast cancer. CSS data used to assess receiving/declining recommended treatments included data that specifically coded whether or not women received a doctors' recommendation for surgery, chemotherapy, radiotherapy, or hormone therapy, and their use of that therapy. Professional abstractors record CSS registry data about 6 months after cancer diagnosis based on the patients' chart review at conventional medicine clinics.

Involvement in treatment decision-making (TDM) assesses participants' perceived Level of Involvement and Participation Congruence in making their cancer treatment decisions.[23,24] Level of Involvement measures the perceived level of involvement in TDM about their cancer treatment overall and specific treatment including surgery, chemotherapy/radiotherapy, tests, complementary treatments, and lifestyle changes. An example item is "How involved do you feel you were in making decision about your surgery? Would you say you were …" The 3-point Likert-type scale score ranges from 0 "much less involved"; 1 "a fair bit"; 2 "very involved"; and 9 "not applicable." In this paper, we dichotomized responses into "very involved" and "not very involved (i.e., much less involved/a fair bit/not applicable)." Participation Congruence evaluates participants perceived correspondence between preferred and actual involvement in TDM in overall and conventional treatments. A sample question is "Would you have preferred to be more or less involved in making decisions about your conventional treatment for cancer?" The 5-point Likert-type scale ranges from 1 "much less involved" to 5 "much more involved." In this paper, responses were categorized as "much less/less involved" "my involvement was just right" and "more/ much more involved." Reliability and validity for this measure have been assessed and found to be moderate suggesting that those who seek to be very involved in TDM about one area of

Table 1
Comparison of Descriptive Statistics Between Receivers and Decliners (N = 427).

	Integrative Oncology cohort (n = 155)			Conventional Oncology cohort (n = 272)		
	Receivers (n = 131) M (SD)/ n (%)	Decliners (n= 24) M (SD)/ n (%)	t / X^2	Receivers (n = 248) M (SD) / n (%)	Decliners (n= 24) M (SD)/ n (%)	t / X^2
Age at diagnosis	52.84 (10.86)	56.54 (10.11)	0.62	54.60 (10.05)	57.00 (8.32)	1.08
Race			5.99*			5.18
Asian	3 (2.3)	3 (12.5)		8 (3.2)	0 (0.0)	
Black	0 (0.0)	0 (0.0)		2 (0.8)	0 (0.0)	
White	126 (96.2)	21 (87.5)		237 (95.6)	23 (95.8)	
Mixed	2 (1.5)	0 (0.0)		1 (0.4)	1 (4.2)	
Marital status			1.10			5.12
Single/widowed/separated	32 (24.4)	7 (29.2)		48 (19.4)	9 (37.5)	
Married/partner	94 (71.8)	17 (70.8)		188 (75.8)	15 (62.5)	
Unknown	5 (3.8)	0 (0.0)		12 (4.8)	0 (0.0)	
Household income			1.44			3.89
< $50,000	45 (36.0)	10 (50.0)		85 (35.7)	13 (56.5)	
≥$50,000	90 (64.0)	10 (50.0)		153 (64.3)	10 (43.5)	
Stage of cancer at diagnosis			12.79*			8.14
State 0	6 (4.7)	5 (21.7)		17 (67.0)	4 (17.4)	
Stage 1	45 (34.9)	11 (47.8)		92 (37.9)	12 (52.2)	
Stage 2	53 (41.1)	4 (17.4)		94 (38.7)	7 (30.4)	
Stage 3	19 (14.7)	3 (13.0)		36 (14.8)	0 (0.0)	
Stage 4	6 (4.7)	0 (0.0)		4 (1.6)	0 (0.0)	
Estrogen Receptor status			4.18*			.74
ER Negative	20 (15.3)	0 (0.0)		25 (10.2)	1 (4.5)	
ER positive	107 (84.3)	23 (100.0)		219 (89.8)	21 (95.5)	
Progesterone Receptor status			.14			.61
PR Negative	27 (21.8)	4 (18.2)		39 (16.7)	2 (10.0)	
PR positive	97 (78.2)	18 (81.8)		195 (83.3)	18 (90.0)	
Site of cancer			2.80			2.06
Left	63 (48.1)	16 (66.7)		131 (52.8)	9 (37.5)	
Right	68 (51.9)	8 (33.3)		117 (47.2)	15 (62.5)	
Overall comorbidity			0.86			0.21
None	47 (35.9)	11 (45.8)		51 (20.6)	4 (16.7)	
One or more	84 (64.1)	13 (54.2)		197 (79.4)	20 (83.3)	
-Cardiac/heart comorbidity			0.01			4.88[1]
No	125 (95.4)	23 (95.8)		235 (94.8)	20 (83.3)	
Yes	6 (4.6)	1 (4.2)		13 (5.2)	4 (16.7)	

* $p < 0.05$. [1] $p = 0.051$.

cancer treatment tend to be involved TDM generally but that there are differences associated with specific types of treatment.[25] In this paper, we did not calculate reliability because we used each individual item in data analysis; we were interested in examining how individuals made decision on each specific treatment.

Satisfaction with healthcare providers assessed participants' perceived satisfaction with their healthcare providers including their conventional oncologist and naturopathic oncologist. Instructions asked women to "rate your satisfaction with the care you received on a scale of 1–10 (where 1 is very dissatisfied and 10 is very satisfied)."

2.3. Procedures

Women in the INO cohort were recruited through six INO clinics in the Western Washington State and these women received both INO care from naturopathic oncologists and UCO care by conventional oncologists and their associated teams of providers. The participating INO clinics were selected using the following criteria: 1) the clinic has naturopathic doctors who are certified by the Fellow of the American Board of Naturopathic Oncology and who agree to function as site investigators, 2) the clinic has ability to adequately conduct study, 3) the clinic agrees to participate in the proper training in study protocol, human subject protection, and informed consent process, and 4) the clinic agrees to regular site monitoring by the third author and provides copies of essential documents. Once participants in the INO cohort were recruited, information on their age and stage at diagnosis, race/ethnicity, marital status, and Estrogen Receptor/Progesterone Receptor status were found in the Cancer Surveillance System (CSS) registry in Western Washington State. By matching the above information, participants for the UCO cohort were identified using the CSS registry and recruited to participate.[22] The Institutional Human Subjects Review Committee of the Fred Hutchinson Cancer Research Center and of Bastyr University approved the study and informed written consent was obtained from each woman. For the secondary analysis, the committees from the above two institutions and that of the University of Washington approved the study and de-identified data were used.

2.4. Statistical analysis

All data were analyzed using SPSS 20 software.[26] First, several decisions were made on proper sample population selection to answer the research questions. The original sample of the Breast Cancer Integrative Oncology Study included 585 women. However, there were 14 women (2.4% of 585) who either did not receive recommended surgery or their data on receipt or non-receipt surgery was missing, so that it was decided to limit data analysis to those who clearly received surgery. Then, there were 54 women (9.5% of the 571 remaining) for whom none of the adjuvant treatments (chemotherapy, radiotherapy, hormone therapy) were recommended after surgery; these too were dropped from the analysis sample. Finally, there were additional 97 women (18.8% of the remaining 517) where at least one treatment was recommended but we did not know if they received it or not. This resulted in a total of 427 women (i.e., who received surgery, who received a recommendation from their medical doctor for at least one adjuvant treatment, and who had a clear record of receiving/not-receiving adjuvant therapy) included in data analysis. Descriptive statistics

including distributions, means, standard deviations, frequencies, and ranges were computed for all study variables. Comparisons were made using t-tests for continuous variables, and X^2 tests for categorical variables. The differences between Receivers and Decliners were conducted first and then analyses examining Receivers and Decliners in INO and UCO cohorts were conducted. As the INO and UCO cohorts differed in their baseline data and we found distinct differences in the predictors of non-receipt associated with INO use, this paper presents four group analyses.

3. Results

3.1. Comparing demographic and Cancer Related factors between receivers and decliners

Table 1 presents descriptive statistics comparing 427 women, 155 women in the INO cohort (131 Receivers and 24 Decliners) and 272 in the UCO cohort (248 Receivers and 24 Decliners). For women in the INO cohort, Decliners of conventional therapy, as compared with Receivers, included more women of Asian descent and women with earlier staged cancer. Every one of these women also had positive Estrogen Receptor status. In the UCO cohort, no significant differences between Receivers and Decliners were found in the variables explored, except that there was a trend of having higher rates of cardiac comorbidity among Decliners.

3.2. Rates of receivers and decliners

Overall, 11.2% (48/427) of women declined at least one adjuvant treatment recommended by their medical doctors after their surgery; 8.8% (22/251) chemotherapy, 10.5% (33/314) radiotherapy, and 13.3% (45/339) hormone therapy. As shown in the Table 2, 15.5% (24/155) of women declined at least one therapy in INO cohort, compared with 8.8% (24/272) in UCO cohort and this difference was statistically significant, $F = 4.39$, $p < 0.05$. More women in the INO cohort declined radiotherapy in the UOC cohort. There was no difference between the INO cohort and the UCO cohort in declining chemotherapy, while there was a trend in hormone therapy.

3.3. Involvement in treatment decision-making between receivers and decliners

Table 3 compares involvement in TDM between Receivers and Decliners per INO and UOC cohorts. Among women in the INO cohort, 62.5% (Test decision) to 100% (Overall treatment decision) of Decliners reported that they were "very involved" and made all decisions for themselves, compared with 48.9% (Test decision) to 81.5% (Lifestyle changes decision) of Receivers. Significantly more Decliners, compared with Receivers, reported being "very Involved" in making overall treatment decisions, surgery decisions, and complementary treatment decisions. Among women in the UOC cohort, 47.8% (Complementary treatment decision) to 87.5% (Surgery decision) of Decliners reported that they were "very involved," compared with 23.5% (Complementary treatment decision) to 64.8% (Surgery decision) of Receivers. Significantly more Decliners reported being "very Involved" in overall treatment decisions, surgery decisions, and test decisions. In contrast, a greater portion of Receivers indicated that they were "Not very involved" in making complementary treatment decisions. No differences were found in participation congruence in overall treatment decision or conventional treatment decision making between Receivers and Decliners in both INO and UOC cohorts. In addition, in testing for an interaction effect of cohort (i.e., INO or UOC) and receipt of treatments (i.e., Receivers or Decliners), we found no statistically significant interaction in involvement TDM on overall treatment, chemotherapy/radiotherapy, test decision, complementary treatment decision, and lifestyle changes decision, suggesting that the differences between the four groups are simply the additive effects of the two main effects.

3.4. Satisfaction with healthcare providers

Table 3 also depicts satisfaction with healthcare providers, which was generally quite good, but Decliners in INO cohort reported significantly lower satisfaction with their conventional oncologists than did Receivers. No difference was found between Receivers and Decliners in their satisfaction with conventional oncologist in UCO cohort. In addition, no difference in satisfaction with naturopathic oncologist was found between groups in both INO and UCO cohorts. That said, subgroup sample sizes for this analysis were small limiting power.

4. Discussion

The rates of declining chemotherapy, radiation therapy, and hormone therapy found in this study are similar to previous findings on women with breast cancer.[2–4,6,27] These rates of declining adjuvant cancer therapies create concerns among healthcare providers as the existing evidence indicates that not receiving all treatments recommended for breast cancer increases women's risk for recurrence about 1.9 times and increase their risk for death about 1.54–5.68 times within 5–10 years of follow-up.[4,28,29]

Among women in the INO cohort, Decliners were more frequently of Asian descent and had more early stage than later stage cancers. As Asian women tend to be familiar with traditional Chinese medicine, which is somewhat similar to complementary and alternative medicine in the U.S., it is possible that some Asian women with breast cancer seek complementary and alternative treatments and choose to decline some recommended conventional treatments because of this familiarity. A previous study found that being Asian Americans was related to not receiving radiation.[30] The finding that women with earlier stage cancers are more likely to not receive recommended treatment is consistent with previous findings,[3,7] and suggests that some women with early stage disease feel that standard recommendations reflect over-treatment.

Decliners, especially those in INO cohort, were very frequently "very involved" in every aspect of TDM more so than Receivers, which

Table 2
Receivers and Intentional Non- Receivers of Recommended Adjuvant Treatments after Surgery (N = 427).

	Integrative Oncology cohort (n = 155)		Conventional Oncology cohort (n = 272)		
	Receivers n (%)	Decliners n (%)	Receivers n (%)	Decliners n (%)	X^2
Recommended at least one adjuvant treatment among chemotherapy, radiotherapy, hormone therapy (N = 427)	131 (84.5)	24 (15.5)	248 (91.2)	24 (8.8)	4.39*
Chemotherapy recommended (n = 251)	88 (88.9)	11 (11.1)	141 (92.8)	11 (7.2)	1.13
Radiotherapy recommended (n = 314)	99 (83.2)	20 (16.8)	182 (93.3)	13 (6.7)	8.08**
Hormone therapy recommended (n = 339)	100 (82.0)	22 (18.0)	194 (89.4)	23 (13.3)	3.75[1]

* $p < 0.05$; ** $p < 0.01$; [1] $p = 0.07$.

Table 3
Comparison of involvement in treatment decision-making and satisfaction with healthcare providers between Receivers and Decliners (N = 427).

	Integrative Oncology cohort (n = 155)			Conventional Oncology cohort (n = 272)		
	Receivers (n = 131) n (%)	Decliners (n= 24) n (%)	X^2	Receivers (n = 248) n (%)	Decliners (n= 24) n (%)	X^2
Level of involvement in making…						
Overall treatment decision			9.50***			5.15*
Not very involved	41 (31.5)	0 (0.0)		90 (36.6)	3 (13.0)	
Very Involved	89 (68.5)	22 (100.0)		156 (63.4)	20 (87.0)	
Surgery decision			5.65*			5.10*
Not very involved	44 (34.4)	2 (9.1)		86 (35.2)	3 (12.5)	
Very Involved	84 (65.6)	20 (90.9)		158 (64.8)	21 (87.5)	
Chemotherapy/Radiotherapy decision			4.19[1]			2.11
Not very involved	57 (44.2)	4 (20.0)		123 (50.6)	8 (34.8)	
Very Involved	72 (55.8)	16 (80.0)		120 (49.4)	15 (65.2)	
Test decision			1.01			6.95**
Not very involved	47 (51.1)	6 (37.5)		130 (54.9)	107 (45.1)	
Very Involved	45 (48.9)	10 (62.5)		6 (26.1)	17 (73.9)	
Complementary treatment decision			5.69*			6.49*
Not very involved	44 (35.8)	2 (9.5)		182 (76.5)	12 (52.2)	
Very Involved	79 (64.2)	19 (90.5)		56 (23.5)	11 (47.8)	
Lifestyle changes decision			1.29			2.87
Not very involved	17 (18.5)	1 (6.7)		98 (39.7)	5 (21.7)	
Very Involved	75 (81.5)	14 (93.3)		149 (60.3)	18 (78.3)	
Participation congruence between preferred and actual involvement in making…						
Overall treatment decision			2.32			1.49
Much less/less involved	4 (3.1)	0 (0.0)		2 (0.8)	0 (0.0)	
Involvement was about right	103 (80.5)	15 (71.4)		211 (86.1)	18 (78.3)	
Much more/more involved	21 (16.4)	6 (28.6)		32 (13.1)	5 (21.7)	
Conventional treatment decision			1.65			0.30
Much less/less involved	5 (3.9)	0 (0.0)		1 (0.4)	0 (0.0)	
Involvement was about right	105 (81.4)	17 (77.3)		216 (87.8)	21 (91.3)	
Much more/more involved	19 (14.7)	5 (22.7)		29 (11.8)	2 (8.7)	
Satisfaction with healthcare providers						
Conventional oncologist[2]	8.45 (2.03)	6.75 (3.04)	6.26*	9.07 (1.58)	8.82 (1.94)	0.38
Naturopathic oncologist[3]	8.80 (1.94)	9.46 (1.13)	1.99	7.83 (2.18)	7.83 (1.72)	0.16

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; [1] $p = 0.051$; [2] n for IO cohort: 96 Receivers vs. 14 Decliners, n for UCO cohort: 202 Receivers vs. 20 Decliners; [3] n for IO cohort: 76 Receivers vs. 12 Decliners, n for UCO cohort: 36 Receivers vs. 5 Decliners.

may be related to the fact that they were making conscious decisions to go against their conventional doctors' specific cancer treatment recommendations. The concentration of these women in the INO cohort may also indicate that these women, who were already highly involved in making treatment decisions to decline adjuvant treatments, sought integrative naturopathic oncologist after their decision. In some cases, Decliners who seek INO care might have been women who were less satisfied with their conventional oncologist and wanted a second or third opinion, compared with Decliners who were in UCO cohort. Considering the high levels of self-reported involvement among Decliners, it is possible that they feel well informed and that further information about the evidence on relative recurrence and mortality risk ratios of declining recommended treatments may or may not help them. In a case study, Frenkel[10] described a woman with stage IIIB breast cancer who received surgery and then made informed decision of declining chemotherapy and chose to use complementary and alternative medicine; the woman considered the rates of survival with (i.e., 32%) or without (i.e., 26%) receiving chemotherapy, side effects, and quality of life in making her decision through active involvement and communication with a family physician.

Low rates of "very involved" in making complementary treatment decisions among UCO cohort might indicate that the option of using complementary treatment was not discussed with the conventional oncologist. In a study with cancer survivors, only 16% of participants believed that their oncologist was well-informed about complementary treatment while 70% reported that their oncologist did not discuss complementary treatment at all.[31] However, over 80% of women with breast cancer use complementary treatments.[32,33] Studies have also found substantial variability in consultation about complementary and alternative medicine use, with finding that range from 2.2% to 71.0% of women with breast cancer who use complementary treatments having spoken to medical doctors regarding their complementary treatment use.[34,35] This highlights the needs for effective patient-healthcare provider communications in the process of making treatment decisions.[10]

Rates of participation congruence reported in this study are much higher than of individuals reporting congruence (56.3%–61%) found in earlier studies conducted in North America regarding oncology TDM [13,16,36] or 80% found among Chinese women with breast cancer living in Hong Kong.[17] Participation congruence is important as it is related to quality of life among women with breast cancer (Andersen et al., 2009), and participating more or less than preferred has been found to be related to decisional regret.[37,38]

It is not clear why Decliners in INO cohort reported significantly lower satisfaction with their conventional oncologist than Receivers in INO cohort or those in UCO cohort. Previous studies found that Decliners tended to view their conventional oncologist as uncaring, insensitive, and unnecessarily harsh.[8,9] When these Decliners in INO cohort, who were unhappy with their conventional oncologist sought oncology certified naturopathic doctors, these women might be unconsciously comparing their conventional oncologist with their integrative naturopathic oncologist who have more time in most office visits to provide necessary physical, psychological, and spiritual supports.

Appointment time with integrative naturopathic oncologist usually lasts 60–75 minutes, compared with 30–60 minutes appointment time with conventional oncologist. Receiving a diagnosis of cancer brings shock and the amount of information that each patient needs to absorb about diagnosis, treatments, and prognosis is too much to grasp.[39] Not

having enough time may prevent conventional oncologists from effective communication and encouragement of patient involvement, which may make patients feel unsupported, especially when women decided to decline recommended treatments. When conventional oncologists need to use language interpreters to communicate with patients, there is potential for further inefficacy, which may result in more communication problems and less use of chemotherapy.[40] In contrast, integrative naturopathic oncologists not only have more time to address women's physical health but also their psychological, and spiritual health by providing individual patient-centered care.[19–21] Therefore, women are more likely feel satisfied with their integrative naturopathic oncologist who discuss nutrition, dietary supplements, mind and body therapy, and lifestyle changes that are evidence-based; receiving this information would empower women. However, this difference may not be observed in UCO cohort because Decliners in UCO cohort did not have the support of integrative naturopathic oncologists.

Several limitations need to be noted. First, very few women in this sample were nonwhite and the sample size for Decliners was small. Being the first study that compared Receivers and Decliners who both do and do not use INO care, there is no way to know if receipt of adjuvant treatment in this sample of INO users is representative of INO breast cancer patients from other regions; this may be worth follow-up research. Second, our CSS data reflect the conventional doctors' initial treatment recommendations as recorded in charts. If patients' involvement in TDM or a changing clinical situation resulted in changes in the doctors' recommendations, it was not reflected in CSS data nor reflected in our study. Third, the tool used to assess Involvement in TDM assessed only patient involvement and did not include answer choice for shared decision making (Ex, Both my doctors and I worked together to made decisions), which has been found to be related to greater satisfaction with information provided, more trust and confidence in their doctors, and improved decision satisfaction and positive patient outcomes.[41–43] Fourth, this paper does not include data on survival, recurrences, hospitalizations, adverse effects and complications in each group of patients. Last, this paper does not include data on why the Decliners in both INO and UCO cohorts made their decision to decline treatment.

5. Conclusion

This study found that women who seek INO care and Decliners in both INO and UCO cohorts were more likely to be "very involved" with their TDM. Receivers and Decliners who seek INO care also tended to report lower satisfaction with their conventional oncologists. We hope oncology healthcare providers can use these findings to understand who might be at risk for inadequate breast cancer treatment. And it may, in fact, be the women, who are Asian descendant, who have earlier stage of cancer, who appear most involved, and who report low satisfaction with conventional oncologist, are at higher risk for nonreceipt and may need the most attention. Supporting and guiding women in the midst of making treatment decisions is vitally important because they are being involved as agents in their own care by making choices that influence their disease prognosis.

Future research needs to include interviewing women who did not receive recommended treatments to understand why Decliners made decision to reject treatments and to what extent they made informed decisions, how to improve patient-provider communication, how to improve women's satisfaction with conventional oncologists, and then supporting the best possible outcomes. Also, examining how involvement in TDM and participation congruence are related to quality of life or decisional regret among Receivers and Decliners would be important. In addition, it is important to examine what Decliners do to manage their cancer and their potential use of alternative treatments and prognosis. Finally, comparing both groups regarding their survival, recurrences, hospitalizations, adverse effects and complications in each group of patients needs to be done. In the case study, Frenkel [10] described a Decliner who was given a prognosis of only 6 months but thrived 10 years with using various alternative and complementary medicine; it would be worth to explore what helped this woman, and what helps other women who have similar exemplary options to flourish.

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