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# Involvement in decision-making about treatment and ovarian cancer survivor quality of life

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## **Abstract**

**Purpose**—This study sought to better understand the long-term effects on women's health related quality of life (HRQOL) of involvement in decision-making about their surgical and chemotherapeutic treatments for ovarian cancer treatment and about follow-up care after treatment.

**Methods**—Using a cross-sectional survey design, a sample of 219 ovarian cancer patient/ survivors from Western Washington who were between 3 months and ten years post-diagnosis were recruited via a mailed survey sent by their gynecological oncologist and interviewed about their ovarian cancer treatment, use of Complementary and Alternative Medicine (CAM), Health related quality of life, and their involvement in decision-making about their cancer treatment and follow-up care.

**Results**—Multivariate regression analyses revealed age, but not stage of cancer to be a significant predictor of perceived involvement in decision-making about ovarian cancer treatment and follow-up. Age also predicted CAM use with older patients using herbal CAM, and younger patients using CAM activities and CAM providers (p < 0.5). Controlling for demographic, disease, and treatment characteristics involvement in decision-making about surgery and follow-up care were associated with better mental health in survivorship (p < 0.05). Involvement in decision-

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making about use of CAM and about lifestyle health changes was associated with greater vitality and better role-emotional health in survivorship (respectively; both; p < 0.05).

**Conclusions**—As has been found in studies of breast cancer survivors, perceived involvement in decision-making about ovarian cancer treatment including surgery and follow-up care after treatment are associated with better quality of life for cancer survivors. Involvement in decision-making about the use of CAM and about changes in lifestyle health practices also appear to help survivors emotional health related quality of life. Prospective studies are needed to determine the mechanisms by which perceived involvement in decision-making about treatment might influence survivor quality of life.

## INTRODUCTION

With growing recognition that patients may benefit from participation in decision-making about their cancer care, health care providers now often seek to provide patient-centered care in which physicians share more information about the patients' condition and possible treatment options sometimes culminating in shared decision-making about which treatments to pursue [1]. Patients with breast cancer may be involved in decisions about the type of surgery they receive [2, 3], the use or avoidance of chemotherapy and radiation [4], and the use of follow-up care [4-7]. While ovarian cancer patients may be being more involved in decision-making about their care than in the past, little of the research examining the effects of patient involvement has extended to ovarian cancer patients and survivors.

Studies of patient involvement in decision-making have often focused on decision-making by women with early stage breast cancer who are candidates for either a mastectomy or a lumpectomy procedure. Studies have found that involvement in such decisions is associated with changes in the frequency with which patients receive certain procedures, and that few patients regret their participation [8-12]. Several studies suggest that such involvement actually improves patients' health related quality of life (HRQOL) in the short-term though few suggest long-term effects. Studies including other types of decision-making around cancer care have found that women who did not receive chemotherapy and perceived no choice regarding chemotherapeutic treatment report lower current HRQOL [4]. Other investigators have found that perceptions of opportunities for decision-making and perceived involvement in decision-making about chemotherapy, and follow-up care are also associated with patient HRQOL in survivorship [5, 13], and that this involvement may be was associated with general health, physical, emotional, and social functioning two or more years post-diagnosis [5].

#### **METHODS**

Study methods and questionnaires were approved by the IRBs of the Fred Hutchinson Cancer Research Center and Swedish Medical Center in Seattle Washington. The authors have no conflicts of interest to declare regarding the work described. We conducted a cross-sectional survey of women with ovarian cancer who received treatment at two gynecologic oncology practices. Those who were believed to be alive, to speak English fluently and were over the age of 21 were considered eligible for this study. Eligible women (total n=450) were approached by mail through their oncologist and asked to participate in the research

study by completing a questionnaire. Survivors were sent a packet containing: a letter describing the study, two copies of the informed consent form, a questionnaire, and a self-addressed postage paid envelope in which to return their consent form and questionnaire. Calls were made approximately two weeks later to individuals diagnosed less than two years previously who did not respond to the initial mailing. Of the 447 women recorded in practice records who met eligibility, 388 had current contact information and were approached to participate. Six were recently deceased and 219 (56.4% of those approached) returned the questionnaire. Of the 219 participating patient survivors, 60 (27.4%) were less than 2 years post-diagnosis, 81 (37.0%) were 2 – 5 years post-diagnosis and 78 (35.6%) were more than 5 years post-diagnosis. Table 1 shows the demographics of responding participants. The majority (62.6%) presented with advanced stage disease, 6.4% with stage II, and 19.18% with stage I disease. Nineteen women (8.68%) did not know the stage of their cancer at the time of diagnosis and seven (3.2%) did not answer the question.

#### Measures

In addition to assessments of involvement in decision-making, survivors were asked their age, other demographic questions, whether they received surgery, chemotherapy, or radiation, for the treatment of their cancer and if they were currently attending visits for ongoing care including hormonal therapies, or specific tests as part of follow-up care after cancer treatment. Women were also asked a series of questions about their use of CAM treatments including herbs and supplements, CAM activities, use of CAM providers (naturopaths, massage therapists, & chiropractors), and about their functional health status using the SF-36 as a measure of quality of life.

**Involvement in Treatment Decision-Making**—Participants were asked five questions about the degree to which they felt they participated in making decisions about several aspects of their cancer treatment and then an overall question to determine whether their level of involvement in decision-making overall was congruent with their desires to be involved or whether they wished to be more or less involved than they were. Although, there are many ways to conceptualize the distinctions between the various aspects of treatment about which women might make decisions, we focused on surgery, chemotherapy, CAM care, lifestyle health, and follow-up for this study. Surgery generally happens early in a woman's course of treatment, and in the case of ovarian cancer often provides the definitive diagnosis and precedes discussion of chemotherapeutic treatment. Chemotherapy treatment decision making is different from surgery in that women can make not only a decision to pursue chemotherapy treatment but once a course is begun they can choose to discontinue it prior to completion, making several opportunities for involvement in decision-making possible. CAM is something that can be initiated by a patient on her own or in consultation with a CAM or conventional provider. Lifestyle health behaviors may also be part of a survivors' care and may include changes to levels of exercise or changes in diet, drinking, or smoking. These decisions, too, are something patients may choose to pursue independent of their care providers. Follow-up care happens after initial treatment is completed and thus may be treated as a separate set of decisions distinct from those occurring during primary treatment.

Patient's perceived participation in treatment decision-making was assessed using one item for each aspect of treatment using questions originally used in [5] with the exception that additional questions were added for CAM care, and lifestyle health. Women were told, "Some women prefer to make decisions about their medical treatment themselves, and others prefer to have their physician or someone else make decisions for them. I want to know how involved you feel you were in making decisions about your care." After this, survivors were asked to rate their perceived involvement in decision-making in their cancer treatment 1) overall, 2) regarding the type of surgery they received, 3) about chemotherapeutic and radiation treatments, 4) about any complementary or alternative medicine they may have chosen to include in their treatment regimen, 5) about lifestyle health behaviors, and 6) about follow-up tests done after the initial treatment. These items were rated on a three point scale from ",1" meaning "Not at all involved – others made decisions for me" to "3" meaning "Very involved – I made all the decisions myself". Survivors were also given the option of indicating that any of these questions were not applicable in their specific case because their treatment required few or no decisions to be made by them or their doctor.

A fifth question regarding involvement in decision-making was also asked of all participating women. This question asked women whether their involvement in decision-making overall was about right (congruent) or whether they wished they had been more or less involved.

**Survivor Health Related Quality of Life**—Health Related Quality of Life (HRQOL) was measured using the SF-36, which assesses several aspects of functional status including physical, social, and psychological functioning [14]. This measure consists of 36 items designed to measure eight dimensions of quality of life and has been found to measure quality of life across a broad range of levels of general functioning, and is sensitive to changes in general life functioning common in relatively healthy populations. [14-16]

## Statistical Analysis

Analyses began with descriptive statistics characterizing the population studied in terms of their age, treatment, follow-up care, HRQOL, and the degree to which they reported being involved in decision-making about their treatment and follow-up care. For these analyses women were divided into groups based on the number of years it had been since their diagnosis with ovarian cancer (less than 2 years, 2-5 years, more than 5 years), examination of demographic and study variables and revealed no differences between the three groups based on survival time. We thus felt it was appropriate to combine the groups for subsequent multiple regression analyses. Bivariate and multivariate analyses were conducted examining predictors of CAM use, and involvement of decision making.

Multiple regression analyses were conducted to examine the study's main hypothesis that involvement in decision-making about specific aspects of treatment and follow-up predicted HRQOL in long-term survivorship. A two-step procedure for hierarchical multiple regression modeling was used. Age, income, education, years since diagnosis (cohort), stage of cancer at diagnosis, the interaction of age and time since diagnosis, the interaction of

stage and time since diagnosis were included as a first step in all analyses. Separate analysis runs were conducted for the eight subscales of the SF-36, the two composite subscales, and the congruence of perceived and preferred involvement.

## **RESULTS**

### **Characteristics of a Population Sample of Ovarian Cancer Survivors**

The sample included a total of 219 women. The average age of the survivors interviewed was 62 years (SD=12). A majority of the sample (72%) had at least some college education. 86.3 percent of the sample was White, with some participation by women who were American Indian (2.7%), Black (.5%), Hispanic (2.2%), Asian (1.9%), or of other ethnicities including multiple or mixed ethnicities (3.5%). Details are presented in Table 1.

The sample was distributed over a period of years since diagnosis (cohort), with 27.4% (n= 60) of the sample having been diagnosed less than two years prior to the interview, 36.99% (n= 81) of the sample having been diagnosed between 2 and five years prior, and 35.2% (n=78) of the sample having been diagnosed more than five years prior. A majority of survivors had advanced disease (62.5%), 51.1% were diagnosed with cancer at a regional stage, and 11.5% with distant stage disease. Almost all subjects n = 209 (95%) reported having at least one surgery to treat their cancer. The majority of the women received some form of chemotherapy (n = 200; 91%). With respect to follow-up care at the time of the interview, 29% of survivors reported continuing treatment of some form. Consistent with prior studies of breast cancer survivors, participating women's self-reported HRQOL did not differ based on years since diagnosis and was within population norms for women of their age.

Approximately 80% of our participants reported engaging in some form of complementary or alternative medicine (CAM) since their diagnosis and 45% reported using some form of CAM substances since their diagnosis. Approximately 41% reported consulting some form of CAM provider a Naturopathic Doctor (ND), an acupuncturist, a chiropractor or a massage therapist since their diagnosis. Potential predictors of CAM use including age, race, education, time since diagnosis, and stage at diagnosis, were examined for each form of CAM (results of these analyses are shown in table #2). Age predicted use of all three forms of CAM in both univariate and multivariate analyses. The association of age with CAM use however differed depending on the kind of CAM use examined; use of herbs and supplements was higher among older patients, and use of CAM activities and CAM providers was higher in younger patients (p < 0.05 in all cases). In univariate analyses education also predicted use of CAM activities with college graduates considerably more likely to use CAM activities (p < 0.01 for the trend), in a multivariate model including age, race, time since diagnosis and stage this relationship was also present but not statistically significant (p = 0.08; NS). Stage at diagnosis predicted use of a CAM provider in a multivariate model with women more likely to see a provider as their stage increased (p < 0.03 for the trend).

## Survivors' Reported Involvement in Medical Decision-Making

Approximately 55% of survivors felt that they were very involved in decisions regarding their cancer treatment overall, with 27% reporting some involvement, and only 5% reporting no involvement (13% reported that there were "no decisions to be made"; see Table 3). About one third (36%) of survivors reported that they were very involved in decisions regarding surgery, with 26% reporting some involvement, and 20% reporting no involvement. As in past studies of breast cancer few women used the "Not Applicable" option, and most women reported that there were decisions to be made about their treatment overall and regarding the surgery they received. In terms of chemotherapy and follow-up care, 40% and 49% (respectively) of subjects reported being very involved in decision-making and 20% and 11% reported no involvement.

With respect to lifestyle health changes self-reported rates of involvement were high with 57% of survivors reporting being very and 21% somewhat involved, few (5%) reported not being involved but 18% felt that there were no decisions about such things to be made. Similarly with CAM decisions 45% of patients reported being very involved, and another 14% reported some involvement, but more felt they were not involved 16%, and 25% felt there were no decisions to be made by them or their doctors/medical providers. When analyses of involvement in decision making about CAM care were done using only those members of the study sample who reported using some form of CAM (n = 175; 80% of the sample), 55% of patients reported being very involved, and another 28% reported some involvement, 6% felt they were not involved, yet a surprising 12% still reported feeling that there were no decisions to be made regarding CAM use.

Survivors were asked to rate their satisfaction with their level of involvement with their conventional treatment 84% reported that they were involved to the right extent, 15% reported that they wished they had been more involved either a little or a lot and less than 1% reported wishing they were less involved.

As illustrated in Table 4, correlations between the items assessing involvement in decision-making ranged from 0.14 to 0.59 and were all statistically significant, suggesting that women who perceive that they were involved in decision-making about one aspect of their treatment tended to perceive themselves as involved in other aspects of their treatment as well. However, women did distinguish between the different aspects of their care in responding to our questions. Not only did the levels of involvement in decision-making associated with different aspects of treatment vary, so did the correlations between responses to these questions. Women's reports of their overall involvement in decision-making appear to have correlated most highly with their reports of involvement in making decisions regarding chemotherapeutic treatment (r = 0.59; p < .0001). Least strongly correlated were women's reports of involvement in decision-making overall and decision making about CAM treatment (r = 0.14; p < 0.05). Decision-making about CAM treatment was, however, associated with decision-making about lifestyle health changes (r = 0.056; p < 0.001).

Demographic and disease characteristics were examined to determine which variables influenced the degree to which women were involved in making decisions about their treatment. Consistent with prior studies stage was not a significant predictor of women's

perceived levels of involvement in decision-making about any aspect of treatment or follow-up care. Age was an independent predictor of perceived involvement in decision-making about CAM care, such that the older a survivor at diagnosis the less likely she was to report being involved in decision-making about CAM.

# Multiple Regression Analyses Examining Survivor Quality of Life

Age and education were significant predictors of the vitality and bodily pain scales of the SF-36 (respectively). Older patients reported more vitality, and more educated patients reported less pain. Current use of treatment also predicted several of the subscales and both of the summary scales consistent with the difficulties known to be associated with active treatment. Having had surgery was associated with less pain, and CAM use was associated with less vitality and more reported difficulties with mental health.

Involvement in Decision-Making and Quality of Life—After controlling for demographic, disease and treatment variables, involvement in decision-making demonstrated some associations with survivor quality of life. There were no statistically significant associations for involvement in decision-making overall, but associations were found for involvement in decision-making about surgery, follow-up, CAM, and lifestyle health. Involvement in decision-making about surgery was associated with better reported mental health, as was involvement in decision-making about follow-up testing ( $\beta$ =.78, p<.01 and  $\beta$ =1.08, p<.01, respectively). Involvement in decision-making about lifestyle health changes was associated with better reported role-emotional health ( $\beta$ =1.92; p<.01), and involvement in decision-making about CAM appears to be associated with greater vitality – although the association did not reach conventional levels of statistical significance ( $\beta$ =1.04; p=.06) overall was not a significant predictor of the physical or mental component summary scales.

#### Congruence of Perceived and Preferred Levels of Involvement

Hierarchical regressions were again conducted to determine if congruence between preferred and perceived involvement in decision-making about conventional care used influenced quality of life after controlling for demographics. Results indicate that congruence did not significantly predict any of the eight SF-36 subscales.

#### DISCUSSION

The purpose of this study was to examine in a sample of women treated for ovarian cancer whether perceived involvement in decision-making about cancer follow-up might influence the long-term health related quality of life, and to explore the possibility that decision-making about a wide variety of aspects of treatment might have effects on survivor HRQOL. Our results suggest that perceived involvement in cancer treatment, including CAM care, lifestyle health behaviors, and follow-up decisions may affect survivors' HRQOL years after treatment ends. We found that self-reported involvement in decision-making predicted aspects of women's self-reported health, particularly mental and emotional health and feelings of vitality.

In addition we evaluated CAM use and found significant variations within this population of ovarian cancer survivors depending on the type of CAM being assessed. Younger age has frequently been found to be a predictor of CAM use and did predict use of CAM activities (such as yoga) and use of CAM providers in our study. However, the use of CAM substances, including herbs and supplements, was associated with older age among patients not younger. Higher levels of education and later stage at diagnosis also appear to be associated with use of CAM activities and providers but not the use of CAM substances.

Although the number of statistical tests performed as part of this examination may have resulted in some type I errors and the identification of a few associations as statistically significant that might be the result of random variation, the consistency of the study results and their consistency with those of prior studies examining breast cancer survivors suggests that broadly speaking perceived involvement does appear to predict better mental and emotional HRQOL In addition, the effects of involvement in decision-making are not limited to early stage breast cancer patients who decide about the type of surgical treatment they will receive, or to decisions about surgical treatment alone. The germane question then, is why perceived involvement in cancer decision-making is associated with long-term quality of life. In some cases, women may, consistent with a General Health Polity Model [17], choose options that maximize their well-being and thus avoid negative consequences they would find most difficult.

Women who are involved in treatment decision-making may be more realistic about expected outcomes owing to the fact that they spent time thinking about each treatment option and the associated benefits and drawbacks. They may also feel like they had control and are less likely to blame another person if they experience regret, feeling that they made the best decision possible. Blaming others for unfortunate life events has been found to predict poorer coping with and adjustment to those events [18-21].

Because the survivors studied here were not randomly assigned to participate in decision-making, both the mechanism by which involvement might affect HRQOL and what women mean when they indicate involvement are unclear and it is not known how involved they were encouraged to be. Women's reports of involvement may reflect differing levels of decisional control over what was done, different levels of involvement in other aspects of their care such as appointment scheduling, and difference in their emotional involvement in the decisions about care.

Survivors' reports of involvement may also be biased by the outcome of their treatment and their current quality of life. It is possible that those survivors with favorable HRQOL two or ten years post-diagnosis are biased, recalling having been more involved in decisions at the time of treatment. Collecting involvement data at the same time decisions are made and comparing them to perceived involvement as a later point in time would be valuable. However, it is interesting to note in this context that survivor involvement in decisions about different treatments differentially predicted aspects of HRQOL. This suggests that reported involvement in decision-making is more specific than just a tendency to use problem-focused vs. avoidance coping, or a general tendency to recall involvement in what later proved to be successful treatment for breast cancer. For example, it is difficult to imagine

why a large number of unrelated survivors with good mental health in survivorship would be a group more likely to report involvement in decision-making about surgery than follow-up care unless that is an accurate report of the aspects of their treatment in which they actually participated.

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# **Research Highlights**

- Involvement in decision-making about ovarian cancer treatment is associated with better mental and emotional health related quality of life.
- Complementary and Alternative Medicine (CAM) use is associated with age, education, and stage of disease.
- Involvement in decision-making about (CAM) use is also associated with better quality of life.

Table 1

Demographic characteristics of participating patients.

Age, mean (SD)         62.62 (12)           Ethnic background         6(3%)           American Indian         6 (3%)           Black or African American         1 (<1%)           White         189 (86%)           Asian, native Hawaiian, or Pacific islander         10 (5%)           Other or unknown         11 (4%)           Highest level of schooling completed         7 (3%)           Some high school         7 (3%)           High school graduate or GED         30 (14%)           Some college or technical school         58 (26%)           College graduate         81 (37%)           Post-graduate degree         41 (19%)           Unknown         2 (<1%)           Time Since Diagnosis         81 (37%)           < 2 years ago		
Ethnic background         6 (3%)           American Indian         6 (3%)           Black or African American         1 (<1%)           White         189 (86%)           Asian, native Hawaiian, or Pacific islander         10 (5%)           Other or unknown         11 (4%)           Highest level of schooling completed         7 (3%)           High school graduate or GED         30 (14%)           Some college or technical school         58 (26%)           College graduate         81 (37%)           Post-graduate degree         41 (19%)           Unknown         2 (<1%)           Time Since Diagnosis         81 (37%)           < 2 years ago		n=219
American Indian   6 (3%)  Black or African American   1 (<1%)  White   189 (86%)  Asian, native Hawaiian, or Pacific islander   10 (5%)  Other or unknown   11 (4%)  Highest level of schooling completed   7 (3%)  High school graduate or GED   30 (14%)  Some college or technical school   58 (26%)  College graduate   81 (37%)  Post-graduate degree   41 (19%)  Unknown   2 (<1%)  Time Since Diagnosis   (2 years ago   60 (27%)  2-5 years ago   81 (37%)  >5 years ago   78 (36%)  Stage of Disease at Diagnosis   (42 (19%))  Stage II   14 (6%)  Stage II   12 (51%)  Stage IV   25 (11%)  Unknown   26 (12%)  Treatment for Cancer   Surgery only   17 (8%)  Chemotherapy only   8 (4%)  Surgery and chemotherapy   192 (88%)  CAM use:   Use of any CAM   175 (80%)  Use of CAM substances   99 (45%)	Age, mean (SD)	62.62 (12)
Black or African American       1 (<1%)	Ethnic background	
White       189 (86%)         Asian, native Hawaiian, or Pacific islander       10 (5%)         Other or unknown       11 (4%)         Highest level of schooling completed       7 (3%)         Some high school       7 (3%)         High school graduate or GED       30 (14%)         Some college or technical school       58 (26%)         College graduate       81 (37%)         Post-graduate degree       41 (19%)         Unknown       2 (<1%)	American Indian	6 (3%)
Asian, native Hawaiian, or Pacific islander Other or unknown Highest level of schooling completed  Some high school High school graduate or GED 30 (14%) Some college or technical school College graduate Post-graduate degree 41 (19%) Unknown 2 (<1%)  Time Since Diagnosis < 2 years ago 60 (27%) 2-5 years ago 81 (37%) Stage of Disease at Diagnosis Stage I 42 (19%) Stage II 42 (19%) Stage III 112 (51%) Stage IV 25 (11%) Unknown 26 (12%) Treatment for Cancer Surgery only Chemotherapy only Surgery and chemotherapy 192 (88%) CAM use: Use of any CAM Use of CAM substances 99 (45%)	Black or African American	1 (<1%)
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Some college or technical school       58 (26%)         College graduate       81 (37%)         Post-graduate degree       41 (19%)         Unknown       2 (<1%)	Some high school	7 (3%)
College graduate       81 (37%)         Post-graduate degree       41 (19%)         Unknown       2 (<1%)	High school graduate or GED	30 (14%)
Post-graduate degree         41 (19%)           Unknown         2 (<1%)	Some college or technical school	58 (26%)
Unknown       2 (<1%)	College graduate	81 (37%)
Time Since Diagnosis         < 2 years ago	Post-graduate degree	41 (19%)
< 2 years ago	Unknown	2 (<1%)
2-5 years ago       81 (37%)         >5 years ago       78 (36%)         Stage of Disease at Diagnosis         Stage I       42 (19%)         Stage III       112 (51%)         Stage IV       25 (11%)         Unknown       26 (12%)         Treatment for Cancer         Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM         Use of CAM substances       99 (45%)	Time Since Diagnosis	
>5 years ago       78 (36%)         Stage of Disease at Diagnosis       42 (19%)         Stage II       14 (6%)         Stage III       112 (51%)         Stage IV       25 (11%)         Unknown       26 (12%)         Treatment for Cancer       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM       175 (80%)         Use of CAM substances       99 (45%)	< 2 years ago	60 (27%)
Stage of Disease at Diagnosis           Stage I         42 (19%)           Stage II         14 (6%)           Stage III         112 (51%)           Stage IV         25 (11%)           Unknown         26 (12%)           Treatment for Cancer         17 (8%)           Chemotherapy only         8 (4%)           Surgery and chemotherapy         192 (88%)           CAM use:         Use of any CAM           Use of CAM substances         99 (45%)	2-5 years ago	81 (37%)
Stage I       42 (19%)         Stage II       14 (6%)         Stage III       112 (51%)         Stage IV       25 (11%)         Unknown       26 (12%)         Treatment for Cancer         Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM         Use of CAM substances       99 (45%)	>5 years ago	78 (36%)
Stage II       14 (6%)         Stage III       112 (51%)         Stage IV       25 (11%)         Unknown       26 (12%)         Treatment for Cancer         Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM       175 (80%)         Use of CAM substances       99 (45%)	Stage of Disease at Diagnosis	
Stage III       112 (51%)         Stage IV       25 (11%)         Unknown       26 (12%)         Treatment for Cancer         Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM         Use of CAM substances       99 (45%)	Stage I	42 (19%)
Stage IV       25 (11%)         Unknown       26 (12%)         Treatment for Cancer         Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM         Use of CAM substances       99 (45%)	Stage II	14 (6%)
Unknown       26 (12%)         Treatment for Cancer         Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM         Use of CAM substances       99 (45%)	Stage III	112 (51%)
Treatment for Cancer         17 (8%)           Surgery only         17 (8%)           Chemotherapy only         8 (4%)           Surgery and chemotherapy         192 (88%)           CAM use:         Use of any CAM         175 (80%)           Use of CAM substances         99 (45%)	Stage IV	25 (11%)
Surgery only       17 (8%)         Chemotherapy only       8 (4%)         Surgery and chemotherapy       192 (88%)         CAM use:       Use of any CAM         Use of CAM substances       99 (45%)	Unknown	26 (12%)
Chemotherapy only         8 (4%)           Surgery and chemotherapy         192 (88%)           CAM use:         Use of any CAM           Use of CAM substances         99 (45%)	Treatment for Cancer	
Surgery and chemotherapy         192 (88%)           CAM use:         Use of any CAM         175 (80%)           Use of CAM substances         99 (45%)	Surgery only	17 (8%)
CAM use:         175 (80%)           Use of any CAM         175 (80%)           Use of CAM substances         99 (45%)	Chemotherapy only	8 (4%)
Use of any CAM         175 (80%)           Use of CAM substances         99 (45%)	Surgery and chemotherapy	192 (88%)
Use of CAM substances 99 (45%)	CAM use:	
	Use of any CAM	175 (80%)
Consulted a CAM provider 89 (41%)	Use of CAM substances	99 (45%)
	Consulted a CAM provider	89 (41%)

Table 2

# Predictors of CAM use.

	Used Herbal	CAM (n=128)		CAM Activity 112)	Visited CAM	Provider (n=89)
	Univariate Model OR (95% CI)	Multivariate Model OR (95% CI)	Univariate Model OR (95% CI)	Multivariate Model OR (95% CI)	Univariate Model OR (95% CI)	Multivariate Model * OR (95% CI)
Age	1.02 (1.00-1.05)	1.04 (1.01-1.07)	0.96 (0.93-0.98)	0.95 (0.92-0.98)	0.96 (0.93-0.98)	0.95 (0.92-0.98)
Race						
White	1.0	1.0	1.0	1.0	1.0	1.0
Non-white	1.08 (0.49-2.36)	1.41 (0.53-3.71)	0.59 (0.27-1.30)	0.62 (0.24-1.62)	0.96 (0.44-2.13)	1.06 (0.40-2.80)
Education						
High school/GED	1.0	1.0	1.0	1.0	1.0	1.0
Some college	1.85 (0.80-4.30)	2.02 (0.73-5.60)	1.5 (0.64-3.51)	0.87 (0.32-2.40)	1.67 (0.69-4.01)	1.51 (0.54-4.27)
College graduate	1.54 (0.70-3.36)	2.01 (0.76-5.27)	2.82 (1.26-6.34)	1.64 (0.63-4.27)	1.80 (0.78-4.13)	1.27 (0.48-3.37)
Graduate degree	1.49 (0.61-3.64)	1.60 (0.54-4.73)	2.61 (1.04-6.52)	1.92 (0.65-5.62)	2.04 (0.80-4.20)	1.87 (0.63-0.56)
p-value for trend	0.55	0.48	0.009	0.08	0.15	0.54
Time Since Diagnosis						
< 2 years ago	1.0	1.0	1.0	1.0	1.0	1.0
2-5 years ago	0.71 (0.36-1.41)	0.78 (0.35-1.71)	1.72 (0.88-3.37)	2.16 (0.99-4.71)	1.69 (0.85-3.33)	2.83 (1.29-6.22)
>5 years ago	0.66 (0.33-1.32)	0.57 (0.26-1.29)	1.37 (0.70-2.70)	2.17 (0.97-4.86)	0.91 (0.45-1.85)	1.66 (0.73-3.74)
p-value for trend	0.26	0.21	0.41	0.08	0.69	0.28
Stage at Diagnosis						
Stage I	1.0	1.0	1.0	1.0	1.0	1.0
Stage II	2.17 (0.62-7.61)	2.29 (0.66-8.38)	2.17 (0.62-7.61)	2.36 (0.62-8.97)	1.0 (0.28-3.53)	0.97 (0.26-3.68)
Stage III	2.26 (1.10-4.66)	1.93 (0.89-4.16)	1.73 (0.85-3.54)	2.66 (1.19-5.98)	1.56 (0.75-3.24)	2.22 (0.98-5.02)
Stage IV	2.15 (0.78-5.96)	1.73 (0.56-5.39)	0.95 (0.35-2.58)	1.81 (0.57-5.73)	1.41 (0.51-3.89)	3.49 (1.08-11.32)
p-value for trend	0.045	0.18	0.58	0.06	0.27	0.03

<sup>\*</sup> Includes all variables listed in the table.

 Table 3

 Reported patient involvement in decisions regarding treatment.

Decision to be Made	Not at all Involved	Involved a Fair Bit	Very Involved	There were no Decisions to be Made
Overall Treatment (n=217)	10 (5%)	59 (27%)	120 (55%)	28 (13%)
Surgery (n=215)	42 (20%)	55 (26%)	77 (36%)	41 (19%)
Chemotherapy (n=218)	43 (20%)	53 (24%)	88 (40%)	34 (16%)
Additional Test and Treatments (n=212)	23 (11%)	55 (26%)	107 (50%)	27 (13%)
Lifestyle Changes (n=214)	10 (5%)	44 (21%)	122 (57%)	38 (18%)
CAM (n=213)	35 (16%)	29 (14%)	96 (45%)	53 (25%)

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Table 4

Pearson correlation coefficients between the involvement in decision-making items.

	Overall Decisions	Decisions Regarding Surgery	Decision Regarding Chemo	Decision Regarding Additional Treatment	Decisions Regarding Lifestyle Changes	Decisions Regarding CAM
Overall Decisions	X	X	X	X	X	X
Decisions Regarding Surgery	r = 0.49 p=0.001	X	X	X	X	X
Decision Regarding Chemo	r = 0.59 p=0.001	r = 0.54 p=0.001	X	X	X	X
Decision Regarding Additional Treatment	r = 0.30 p=0.001	r = 0.37 p=0.001	r = 0.42 p=0.001	X	X	X
Decisions Regarding Lifestyle Changes	r = 0.27 p=0.001	r = 0.24 p=0.001	r = 0.23 p=0.001	r = 0.46 p=0.001	X	X
Decisions Regarding CAM	r = 0.14 p=0.04	r = 0.15 p=0.02	r = 0.24 p=0.003	r = 0.31 p=0.001	r = 0.56 p=0.001	X

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