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The Unsuspecting CAM User:

Cancer patients and the changing nature of holistic health

A. M. Kabel & L.P. Johnson

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Abstract

The number of cancer patients using complementary and alternative medicine (CAM) in the United States is growing, yet little is known about the meaning these activities have for users. Current literature supports the assumption that stigma surrounding CAM and holistic health practices are responsible for the reluctance of many cancer patients to self-identify as CAM users. This study explored the frequency of use, and familiarity with CAM among 26 female patients at a Midwestern oncology clinic. Findings suggest that patients need to be asked about CAM use multiple times and in multiple formats to gain an accurate assessment. Also, the assumptions about stigma may no longer be the reason patients are less than forthcoming about CAM use. The rise of integrative medicine and shifting boundaries of the holistic health movement may be equally, or in some cases, more responsible for the reluctance for CAM users to self-identify.

Keywords: *CAM; women with cancer; integrative medicine*

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I. Introduction

The estimated number of people who have been diagnosed with cancer in the United States has been on a steady increase for the past decade. It is estimated that the number will grow beyond 13 million in the next decade (Eheman et al., 2012 and Alekruse et al., 2010). In 2011, Parry and colleagues published a seminal article calling for greater research on cancer survivorship and its conditions, especially as the population of survivors age. In recognition to the growth of this population, in 2012, the American Cancer Society released its “Facts & Figures” report devoted entirely to the cancer survivor population (ACS, 2012).

Continued advances in cancer detection and treatment strategies have increased the numbers of individuals living years beyond diagnoses (for some cancers), in some cases beyond 5 years (Aziz et al., 2003; ACS, 2003). Living with cancer often means coping with increased stress, poor health-related quality of life and unfulfilled psychosocial needs (Monti et al., 2005, National Research Council, 2008). Complementary and alternative medicine, or CAM therapies, have become increasingly popular among cancer patients and survivors, as a way to address the various shortcomings of conventional biomedical treatment. According to an analysis done by Mao and colleagues, cancer survivors were more likely than the non-cancer control population to cite that they were using CAM because “medical treatments did not help” (Mao et al, 2011: 14, figure 2). The areas where biomedicine is failing are far reaching. In Mao’s study, the common uses for CAM among cancer survivors are:

For wellness or general disease prevention; to enhance energy; to enhance immune function; to treat pain-related symptoms (including joint pain/aching, neck pain, back pain, other musculoskeletal, regular headaches, severe headaches/migraines); to treat psychological distress (including stress, anxiety, or depression), and to treat insomnia (Mao et al, 2011: 10).

In a recent report assessing the care of cancer survivors and promoting better rehabilitation efforts on their behalf, Alfano and others (2012) stated the following:

Depending on the specific treatment exposures, survivors of cancer can face numerous adverse consequences of cancer treatment, many of which are amenable to rehabilitation interventions. These include fatigue, depression, anxiety, fear of recurrence, cognitive dysfunction, pain syndromes, peripheral neuropathy, sexual dysfunction, balance and gait problems, upper or lower quadrant mobility issues, lymphedema, bladder and bowel problems, stoma care, problems with swallowing or dysphagia, and communication difficulty (2012: 905).

CAM therapies are defined as interventions neither widely taught nor generally available in U.S. hospitals (Eisenberg et al., 1993). The holistic approach of CAM is thought to be among its attractive features, for example, “Patient-centered care and patient empowerment are primary components of these [CAM] fields, as is the commitment to address the mind, body, and spiritual aspects of health” (Maizes, Rakel & Niemiec 2009: 278). Total CAM expenditures in the U.S. are in the billions of dollars, the majority of which are out-of-pocket costs (Eisenberg et al., 1993). The majority of CAM-using cancer patients and survivors combine them with conventional therapies (Boon et al., 2000; Richardson et al., 2000). In a study of CAM use by breast cancer and gynecological cancer patients in Texas, Navo et al, stated the reasons for using CAM among their study population was diverse:

A higher proportion of patients in the MBC [Multidisciplinary Breast Center] stated their reasons for CAM use to be to improve quality of life and to decrease the adverse effects of other medications that they may be using. Also, 15% of patients in the GOC [Gynecological Oncology Center] stated that their reason for use was to treat their cancer. We found a wide variety of CAM in various formulations and doses being used for multiple indications. Identifying the most frequently used CAM was just one approach to prioritize the agents to evaluate first in the laboratory for drug interactions (2004: 676).

Patient self-reporting to physicians of CAM use varies by cancer site, gender and other factors; from little to no reporting to as many as half of cancer patients reporting (Mao et al, 2011 and Yates et al 2005). Breast and ovarian cancer survivors are reported to be the most likely to use CAM (Gansler et al, 2008). According to a 2000 report from the White House Commission on Complementary and Alternative Medicine Policy, the use of CAM is growing among Americans in general however, most people use it “in conjunction with, rather than as a replacement for, conventional medical therapy” (White House Commission 2000). CAM modalities are as diverse as the patients using them. In the study of patients undergoing cancer treatment by Yates et al., some of the modalities inquired about were: “exercise, prayer, relaxation, chiropractic, massage, imagery, spiritual healing, diets, herbal medicine, mega-vitamins, Self-help groups, hypnosis, and acupuncture” (2005:808).

Patients are using CAM to treat well-known, but not always well-managed side effects of active treatment, and survivors are using CAM to treat lingering effects of the completed treatments and the more poorly understood late effects of cancer and its treatments. Treatments for side effects and late effects are intended to help patients adjust to their ‘new normal’, however, patients are increasingly expressing their dissatisfaction with the effectiveness of these treatments alone, and frustration with the lack of appreciation for gaps that exist in some areas such as mental health, fertility, and legal/financial issues (Ehrenreich, 2001, Sulik 2011, King, 2008, Blank, 2009). Driving much of the survivor activism is younger survivor advocates in organizations such as the LiveStrong, Stupid Cancer and Young Survival Coalition. However, the 2012 publication of the ACS cancer survivor document and the 1996 creation of the National Cancer Institute’s Office of Survivorship show that interest in cancer survivor issues is becoming more mainstream.

In 2005, the Institute of Medicine produced a comprehensive report called “From Cancer Patient to Cancer Survivor: Lost in Translation” intended to raise awareness of medical professionals’ lack of understanding of and communication about cancer survivors’ legal, medical, social, economic and psychological problems. Some of the report’s recommendations (ie, the “Survivorship Care Plan”) have been implemented by cancer centers, but evidence-based treatments for long term effects for cancer are less widely known by providers. As physicians increasingly accept cancer survivorship as a distinct phase of cancer, the body of research aimed at understanding the long term physical and mental impacts of cancer treatment will continue to grow. According to the ACS report about survivors, some of the longer term impacts of cancer are:

Long-term and late effects may be emotional (e.g., anxiety, depression) and/or physical (e.g., heart, lung and kidney damage, mental impairment, and infertility). Cancer survivors are also at risk for recurrence of the original cancer or the development of a new, biologically distinct, second primary cancer, with risk dependent on the original type of cancer, stage of disease, and treatments received (2012: 24)

Cancer treatments vary and their long term impacts can vary by treatment (Alfano et al, 2012; Parry et al., 2011; Fossa et al, 2007; Bennett et al, 2010). According to Zucca et al (2012) very few survivors have pain or other issues, suggesting an additional facet to the survivorship experience. Increasingly, we understand that the survivorship outcomes also are impacted by race, class, and younger age at treatment (ACS 2012).

Weaver and others (2010) investigated the prevalence of cancer survivors doing without health care because of costs concerns. This research outlined the following: 7.8% forgo medical care, and 9.9% forgo prescription medications, which is “greater than that reported for the US population in general, (5.2% and 7.2%, respectively) for the year 2005” (Weaver et al., 2010: 3501). Also in this study, preliminary evidence confirms that race, type of cancer, and years since diagnosis impact a survivor’s decision to forgo health care because of cost concerns. This information appears counter-intuitive to the well-documented and extensive use of CAM among people with chronic conditions including cancer (Monti, et al., 2002) and implies that compliance and adherence issues do not parallel CAM participation among American cancer patients/survivors.

The widespread knowledge about CAM-using patient reluctance to self-identify has often been attributed to the stigma surrounding holistic approaches to health (Fennel et al., 2009; Rose 2009; Sewitch et al., 2008; Lewith 2008; Rojas-Cooley and Grant 2009; Rhode et al., 2008). This explanation is complicated by recent studies that suggest the under reporting of CAM use is due to a wide variety of factors, including patients not considering CAM a type of ‘real’ medicine (Navo et al., 2004). In a study by Zhang et al., of family medicine patients, there were significant numbers of providers who did not feel that they understood or could adequately explain a variety of CAM modalities, and a literature review by Sewitch et al., (2008) found that confusion about, and negative attitudes toward CAM modalities was common across a number of studies for physicians (but not necessarily for other staff). This literature review also indicated that physicians are increasingly interested in learning about and understanding CAM modalities. The recent growth of CAM use and popularity of integrative medicine provide an opportunity to reexamine the stigma assumption. This study examined the familiarity with, frequency of, and willingness to admit CAM use among female cancer patients at a Midwestern oncology clinic. The specific types of CAM therapies used were explored to gain insight into the motivations for use.

II. Methods

This survey was designed to determine if cancer patients used CAM therapies and, if so, which therapies. A descriptive survey design was developed and data was collected through a questionnaire. We hypothesized that patients tend to under-report CAM utilization, requiring redundancy (asking same question multiple ways) in the survey design. This embedded redundancy was intended to more accurately capture participant experience with CAM therapies. IRB permission was secured before any recruitment or data collection took place.

A convenience sample of 26 newly diagnosed or relapsed female cancer patients were recruited at a women’s cancer clinic in the Midwest. Recruitment took place over approximately three weeks and participants were recruited in the waiting area of the clinic. The oncologist to whom these patients were referred (and where these data were collected) was female and had a reputation for being supportive of patients using CAM therapies.

Individuals interested in participating in this study were given more information, consented and surveyed in a private room. Volunteers were assured that input was voluntary, confidential and would have no impact upon their right to continue treatment at the clinic. One volunteer was recruited and later dropped out of the study due to lack of cancer diagnosis. All study participants were invited to share their history and experiences regarding the use of CAM therapies via the guided questionnaire. Patients needed to be at least 18 years and older with no language barrier or inability to read. Results were entered into a spread sheet and tabulated.

Participants

The participants (n=25) were all female cancer patients (See table 1 for type and frequency of cancers). Their ages ranged from 38 to 91 years, with a mean age of 57.84 and median of 57.0. 23 self-identified as white, non Hispanic, and 2 as Hispanic women.

Diagnosis	Frequency
Breast	2
Cervical	3
Endometrial	3
Melanoma	1
Ovarian	10
Other	1
Uterine	4
Breast & Ovarian	1

Findings

Our findings supported existing literature regarding the prevalence of CAM use among the patient population and confirmed patient reluctance to admit using CAM therapies. Twelve (48%) of the participants answered “no” when asked if they used CAM, but upon further questioning, described using one or more of these therapies. For the participants as a whole (n=25), the therapies they used included: acupuncture (4), meditation (6), supplements (21), prayer (9), chiropractic (2), massage (12), yoga (8), aroma therapy (5), organic diet (2), and reflexology (3). Participants reported using the following medicinal plants: chamomile tea, aloe vera, Echinacea, elderberry, green tea, rosemary, St. John’s Wart, garlic, ginger, milk thistle, lavender, evening primrose oil.

Patients used CAM alongside traditional therapies and only 2 received information about CAM from health care providers. The rest reported using various media or other sources for information about CAM. None of the participants reported using traditional Chinese medicine or Ayurvedic therapies. Among the patients self-identifying as non-CAM users, they reported using aloe and aloe vera, chamomile, cranberry, Echinacea, evening primrose oil, green tea and garlic, among other supplements.

Of the ten participants diagnosed with ovarian cancer, nine, or 90% reported using CAM therapies. Specifically, they reported using herbal supplements (9), following a special/macrobiotic diet (2), receiving acupuncture (3), meditating (4), praying for health (3), receiving massage therapy (2), practicing yoga (5), reflexology (2), reiki (1), aroma therapy (1) and using a natural healer (3).

III. Discussion

About half of our participants denied CAM use when first asked, but revealed participation in several CAM therapies after being asked multiple times. The majority of participants did not discuss the use of these therapies with their physicians and physicians did not typically ask patients about CAM. This mirrors what has been documented in current literature on provider-patient discussions about CAM (Eisenberg, 1997; Boon et al., 2000; Richardson et al., 2000, Sewitch et al., 2008). This pattern can be interpreted as indicating either a health literacy

barrier, (lack of understanding about these activities [Fennell, 2009]) or a concern about being exposed as a CAM user (stigma), and being judged negatively by the provider (Rojas-Cooley and Grant 2009; Rhode 2008; Sewitch et al., 2008). One possible explanation for this is that the CAM-using patients who do not self-define are looking for the more passive types of CAM.

Passive CAM use includes supplements and activities that do not require a significant amount of effort, research or lifestyle change, such as taking a pill or receiving a treatment. CAM use is typically thought about in terms of an active health-related decision making however, and not associated with passive behavior. Navo et al., (2004) would agree; their interpretations suggest that CAM use represents patient empowerment and is not mentioned at doctor visits because it is not necessarily considered medicine by its users:

Of the patients defined as CAM users, most gathered information about CAM on their own by using resources such as the internet or the media. CAM users also seemed to look to their social support like friends and family for their opinion. Not surprisingly, healthcare professionals were third in line when listed as a likely resource for patients. This information demonstrates that patients are making an effort to take an active role in their own healthcare. Also, less than a third of all patients considered CAM a type of medication, which may contribute to the low incidence of reporting of CAM use to healthcare professionals when giving a medication history. The majority of patients who spoke to any healthcare professional felt positive about their conversation. Of those who had not discussed CAM with a professional, the most common reason was that it was never brought up during their visit (Navo et al., 2004: 676).

Participants were not uniform in their attitude toward or use of CAM. Participants diagnosed with ovarian cancer represented the largest diagnostic group in our study. 90% of the ovarian cancer patients in our study reported using some form of CAM. The literature suggests breast and ovarian cancer patients are the most likely to use CAM, and survivors of distant, or more advanced disease are more likely to use CAM than patients with local disease (Gansler et al., 2008). This is perhaps due to the fact that ovarian cancer is infrequently diagnosed in its early stages, resulting in newly diagnosed patients who are further along the illness trajectory, the greater uncertainty of treatment outcomes with ovarian cancer specifically, and cancers detected at later phases in general. These patients were as a group, the least reluctant to self-identify as CAM users among the participants in this study.

The reluctance of CAM users to self identify reflects the shifting boundaries of the holistic health movement's transition toward integrative medicine. Herbal supplements and alternative therapies were once (and not long ago) considered marginal among clinicians, however many of these practices have been absorbed into biomedicine and are mainstream care options (Rose et al, 2009; Lewith et al., 2008; Giordano et al 2002). Herbal supplements once found only in specialty shops are now mass produced and widely available. Our participants purchased and consumed products recommended to them by friends, or health professionals, perhaps without realizing that these products were associated with alternative or holistic health.

Participants used CAM alongside conventional treatment, and for the for the most part did not see the use of these therapies as a challenge to biomedicine. In these instances, CAM became shorthand for complementary methods used in conjunction with traditional biomedicine or allopathic medicine and may have been incorporated into their "pathways of survivorship" (Blank 2009: 425). Patients did not feel the need to inform, consult or seek permission from the oncologist about their CAM use, reflecting the changing expectations for provider-patient communication. CAM use was not an issue that threatened their status as 'good' cancer patients because they were

seeking out supplements and therapies they believed would support their overall well being.

IV. Conclusion

With advances in cancer prevention education, early screening awareness and treatments for cancer, the number of cancer people being treated for, and surviving cancer, has grown dramatically since President Nixon's declaration on the war against cancer in 1971 (marked by the signing of the National Cancer Act). Although five-year survival rates vary by cancer types, stages, ages, race and class, many of those diagnosed with cancer today can expect to live long and full lives. These lives, however, are not free of challenges. It is increasingly understood that many (but not all) cancer patients/survivors deal with a myriad of emotional, financial, physical, legal and mental burdens that result from their cancer diagnoses. So, as the technologies for cancer detection and treatment have expanded since Nixon's declaration, the science surrounding the long term and late effects of cancer treatment is, unfortunately, lagging. The call to alleviate this delay in scientific and clinical understanding of survivorship has grown louder, and, as signaled by the 2012 American Cancer Society report about the growing survivor population, is being heard by those in the oncology community.

In roughly the same time period that we have seen this exponential growth in cancer outcomes, we have seen a slower, but equally steady, use by the general American population of treatments called CAM, or complementary and alternative medicine. This movement to use CAM therapies was fueled by the patient empowerment movements that began in the 1970s. The range of treatments called CAM, is wide in application and availability, however, more Americans are admitting to its use. CAM use is not necessarily a seen as a subversion of mainstream medicine—studies of CAM users frequently point to the fact that CAM is often seen as a supplement, rather than replacement for, traditional Western biomedicine. The reasons for using CAM vary by patients and, even by illness, but CAM users often seek to “fill in the gaps” where traditional medicine has missed, or not completely addressed, a medical issue or symptom. As with the larger population, cancer patients/survivors seek to use CAM for these same reasons. The cancer experience can be disruptive for some, and the late and long term cancer effects can impact several domains of the lives of patients/survivors and, therefore, it makes sense that some gravitate to these more self-empowering and holistic approaches in their journey to their ‘new normal’. In many studies, breast cancer and gynecological cancer patients seem to be the most willing cancer patients to admit to CAM use.

However popular these modalities have become, the patient-provider communication about the use of CAM remains difficult or non-existent. Studies about average Americans and cancer patients/survivors consistently show that care providers do not routinely ask about and understand CAM use and patients do not regularly initiate a conversation about CAM. These studies about CAM use among various patient populations point to a multitude of reasons—poor provider understanding, provider bias, health literacy, poor health communication, patient embarrassment, and patients not understanding that CAM is in fact medicine. Of the 25 women we surveyed, only two reported receiving information about CAM from a health care provider.

It is in this context that we undertook a study aimed at understanding the prevalence of use of CAM modalities among female cancer patients/survivors in a Midwestern cancer specialty practice. This was a practice headed by a female physician known to be open to discussion about cancer patients' use of CAM. The study involved a voluntary survey of patients from this clinic. The survey was administered in person to 26 patients (with one dropping out). With the heightened visibility of CAM methods in the larger American culture (and, therefore, the possibility that patients do not easily recognize certain acts and procedures as CAM), the survey had built into it

repetition and detail in order for the researchers to be assured that they had a clear picture of CAM use among this population. Among the population studied, CAM use was common and included a number of different kinds (with no use of Chinese or Ayurvedic medicine). Analysis of the survey data revealed that people who initially did not classify themselves as CAM users were in fact, using products and services that fall under the CAM categories. These were “unsuspecting” CAM users.

Upon closer inspection, a majority (90%) of ovarian cancer patients/survivors in the study were enthusiastic supporters of CAM, using an extensive menu of modalities, many at the same time. This finding is perhaps unsurprising—as SEER data points to more frequent late diagnoses of ovarian cancer patients. In popular media, ovarian cancer is sometimes referred to the “silent killer” because its symptoms are often mistaken for other conditions, such as stomach pain, fullness, gas/bloating, that are treated with OTC therapies. These ovarian cancer patients had an attitude that stands in contrast to the other participants in this study.

Implications

It is imperative that health professionals find multiple ways to inquire about the use of CAM therapies with their cancer patients. Direct questioning is not likely to yield accurate results for several reasons. Patients are not necessarily afraid to tell physician/provider about CAMs, although that is possible. Patients likely do not think of the mass produced, widely available products and therapies they use as CAM, or as actual medicine. Patients are curious about natural healing products and the realities of living with cancer and cancer survivorship can leave them feeling unwell or vulnerable to further health problems. This vulnerability may cause CAM therapies to appear more attractive to cancer patients and survivors. It is possible that cancer patients in general and specifically ovarian cancer patients used CAM before diagnosis to treat commonly mistaken symptoms.

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