



## Expected and perceived efficacy of complementary and alternative medicine: A comparison views of patients with cancer and oncologists



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### ARTICLE INFO

#### Article history:

Received 17 March 2016

Received in revised form 15 July 2016

Accepted 29 July 2016

Available online 29 July 2016

#### Keywords:

Complementary and alternative medicine  
Discrepancy  
Oncologist  
Cancer patient  
Efficacy

### ABSTRACT

**Background & aims:** This study sought to identify discrepancies between the expectations of patients with cancer and oncologists regarding the efficacy of complementary and alternative medicines (CAMs), and to determine how patients evaluate CAM efficacy after its use.

**Methods:** Data from the Cancer Patient Experience Study, a nationwide survey, were used. Seven subdivided efficacy domains were included in the survey. An oncologist-patient matching analysis was done to assess the concordance of CAM efficacies between oncologists and patients with cancer. In addition, the patients' expectations of CAM efficacies were compared before and after use.

**Results:** Out of 719 participants, 201 patients with cancer (28.0%) reported using CAMs. The patients with cancer generally tended to be more positive about CAM efficacies than the oncologists. The largest discrepancy in efficacy perception was found in the efficacy domain of survival benefit, which included complete disease remission and prolonged survival. Many patients reported that they did not experience the positive efficacy they had anticipated before use. However, a substantial proportion of patients indicated that CAMs were as effective as they had expected, even though there is little evidence supporting the CAM efficacies.

**Conclusions:** There was a marked discrepancy and a lack of concordance in expectations of CAM efficacy between patients with cancer and oncologists. Better communication between the patients and oncologists regarding CAM efficacy would be needed to make the patients to have shared expectations, and to reduce unnecessary CAM use.

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## 1. Introduction

Currently, the use of complementary and alternative medicines (CAMs) in patients with cancer is widespread and increasing.<sup>1–4</sup> Accordingly, an enormous amount of money is being spent in this field.<sup>1,2</sup> In a survey conducted in Korea, approximately 78.5% of

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<http://dx.doi.org/10.1016/j.ctim.2016.07.005>

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patients with cancer used at least one type of CAM, with a mean monthly cost of \$1100 per person.<sup>2</sup>

However, most clinically implemented CAMs have limited scientific evidence, which is inconclusive to recommend their use.<sup>5–7</sup> Even CAMs may induce unwanted negative consequences for conventional cancer treatment, not only directly but also by interfering with the metabolism and the physiological response of conventional treatment.<sup>8–10</sup> Therefore, clear communication about CAM use between the patient and their physician is important when deciding on cancer treatment.

The use of CAMs is largely driven by expectations of their efficacy by patients with cancer.<sup>11,12</sup> Some previous studies revealed that patients with cancer often have much higher expectations of CAM efficacy than physicians.<sup>3,13,14</sup> However, these studies did not match the patients with their doctors to assess the concordance of expected CAM efficacies.

In addition, experienced efficacy after CAM use are the basis for the decisions of patients with cancer on continued CAM use,<sup>15</sup> which can also affect the initiation of CAM usage in other patients with cancer.<sup>3,16</sup> Therefore, it is necessary to know how patients evaluate CAM efficacies after their use compared to their initial expectations prior to CAM use. However, to our knowledge, there are no studies comparing the expected efficacies of CAMs with their experienced efficacy after CAM use in patients with cancer.

Understanding both the patients' and physicians' perspectives on CAMs would help establish better decision making for CAM use. In this study, we compared (1) the expected efficacies of CAMs in patients with cancer and the perceived efficacies of CAMs in their oncologists with a matched patient-physician sample, and (2) the expected and experienced CAM efficacies in patients with cancer before and after use, respectively.

## 2. Materials and methods

### 2.1. Study design and subjects

This study was conducted as part of the CaPE (Cancer Patient Experience) Study, an annual nationwide survey in Korea, which assesses medical care and treatment options for cancer. This study was supported by the Ministry of Health and Welfare, and conducted by the National Cancer Center. It was approved by the institutional review board of the National Cancer Center (Grant No. 1210150).

The survey was conducted in 2012 using oncologist-patient with cancer-caregiver matched triads, to explore the different views of oncologists, cancer patients and family caregivers in medical care and treatment. Trained nurses helped the participants to complete and understand the survey questionnaires. The detailed process for recruiting oncologists, patients with cancer, and their caregiver has been described previously.<sup>17</sup> Briefly, a total of 144 board-certified oncologists were recruited from 13 cancer centers. Each oncologist was asked to recruit 6 consecutive patients who were accompanied at the visit by a family caregiver. Among the 144 oncologists, 134 completed the study survey (93.1% participation rate). From the 960 patients, 725 dyads and their caregivers completed the survey (75.5% participation rate).

### 2.2. Survey questionnaires

The CAM questionnaire was administered only to patients and physicians, in order to have matched analyses. The English version of the survey questionnaires is provided as online-only Supplementary material.

The patients were first asked whether they had ever used CAMs after their cancer diagnosis for cancer care. If the answer

was 'Yes. But not now' or 'Yes. I am currently using', they were asked to describe the type of CAM used. We presented 8 CAM categories in the survey questionnaire, which are designated as CAM Therapies by the Office of Cancer Complementary and Alternative Medicine, The National Cancer Institute (NCI)<sup>18</sup>: (1) Alternative Medical System (e.g., acupuncture, moxa cautery, cupping therapy, ayurveda, traditional Chinese medicine, homeopathy, naturopathy); (2) Energy/Exercise Therapy (e.g., tai chi, qi gong, yoga); (3) Manipulative and Body-Based Methods (e.g., chiropractic manipulation, massage, osteopathic manipulation); (4) Mind-Body Interventions (e.g., meditation, hypnosis, biofeedback, imagery, relaxation, music therapy, aromatherapy); (5) Spiritual Therapies (e.g., intercessory prayer and spiritual healing); (6) Dietary Therapy (e.g., vegetarian diet, Gerson diet); (7) Nutritional Therapeutics (e.g., vitamin, melatonin, mineral supplement, herb and herbal extract); and (8) Others. Some category modifications were made to take into account the prevalence and general concept of CAMs in Korea. For example, energy and exercise therapy were combined into a single category since Koreans tend not to conceptually distinguish these two examples. Dietary therapy and nutritional therapeutics were separated, as many Koreans do not equate specific dietary therapy and nutritional supplements. The 'pharmacological and biologic treatments' NCI category was not included in the response options, since these treatments (e.g., antineoplastic, 714X, low dose naltrexone) are generally not available or practiced in Korea. Since patients could use more than one CAM type, multiple responses were allowed.

The patients were asked about their expectations on CAM efficacies before use on the following items: (1) complete remission of disease; (2) life prolongation; (3) pain or symptom relief; (4) regaining physical strength; (5) immune function improvement; (6) psychological and emotional support for the patient; and (7) psychological and emotional support for their family caregivers. Response options were yes or no. Simultaneously, they were also asked whether they experienced CAM efficacy on the same items after CAM use. Finally, the patients were asked if they had discussed about CAM use with doctors.

The physicians were asked about their opinions on the general efficacy of CAMs using the same set of questions. Also, they were asked if they had discussed about CAM use with their patients.

In addition, the survey collected the respondents' socio-demographic and medical information. Further, the primary cancer diagnosis using the Surveillance, Epidemiology, and End Results (SEER) stage criteria was retrieved from the hospital information systems of each participating center.

### 2.3. Statistical analysis

A descriptive analysis was performed for the respondents' baseline characteristics. We compared the proportions of positive responses to the expected efficacy items in both medical oncologists and surgical oncologists. Radiotherapy oncologists were excluded in the analysis due to possible bias by the small sample size of included radiotherapy oncologists ( $n = 7$ ). The proportion of positive responses to the expected efficacy items from the oncologists and the patients was compared using a chi square test. After matching the patients to their own doctor (multiple patients with cancer could be matched to a single oncologist), a Cohen's Kappa and the  $p$  values from the McNemar test were calculated to assess the concordance of the responses between the oncologist and their own patients. The proportions of positive response to items regarding the expected and experienced CAM efficacies were compared using a McNemar test. All statistical analyses were conducted using STATA software version 14.0 (StataCorp., TX). A  $p$  value of less than 0.05 was considered statistically significant.

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