



Research paper

Patient health literacy and patient-physician communication regarding complementary and alternative medicine usage

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ARTICLE INFO

Article history:

Received 10 June 2016

Received in revised form 10 February 2017

Accepted 10 February 2017

Keywords:

Complementary and alternative medicine

Communicative and critical health literacy

Japan

Mixed methods

Patient-physician communication

Chronic disease

ABSTRACT

Introduction: In Japan many patients have chronic diseases and although complementary and alternative medicine (CAM) has been drawing public attention, the relevant factors regarding patient-physician communication are still unclear. The aim of this study was to investigate CAM disclosure, and examine the relationship of communicative and critical health literacy (HL) in patient-physician communication with respect to CAM use in Japanese patients with chronic diseases.

Methods: A semi-structured interview survey was conducted with 35 Japanese patients with chronic disease. In addition, a questionnaire survey was conducted via 14 patients associations to explore patients' experiences of disclosing CAM to physicians and any reasons for non-disclosure.

Results: Interviews suggested that the reasons for not disclosing CAM use to physicians was the perceived lack of physician understanding, fear of angering the physician, reticence to discuss this issue, and no time to discuss. The survey suggested that of the 428 respondents, 65.3% had discussed CAM with their physicians. A logistic regression analysis of factors related to disclosure revealed that angering the physician ($p=0.001$, $OR=0.47$), how to address the issue ($p < 0.001$, $OR=0.41$), lack of time ($p=0.006$, $OR=0.54$), HL ($p=0.023$, $OR=1.63$), and effects of refutation ($p=0.003$, $OR=0.33$) had multivariate associations with disclosure.

Conclusions: Patients with high HL were more likely to disclose CAM to their physicians, but they were less likely to experience disclosure if they were afraid of effects of refutation.

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1. Introduction

Complementary and alternative medicine (CAM) began to draw public attention in the 1990s. This was a result of national efforts to explore ways of reducing medical costs, enhancing the health attitudes of the public associated with recent aging and changes in disease structure. According to the United States National Center for Complementary and Integrative Health (NCCIH) [1], CAM is defined as a group of diverse medical and healthcare systems, practices, and products that are not presently considered part of conventional medicine.

The disease structure is also changing in Japan where 14 million patients have chronic diseases [2]. Some of them incorporate CAM into their disease self-management [3]. CAM is practiced at 73% of the medical institutions and its usage rate is 76% [4] and 57% [5]. The Japanese Society for Complementary and Alternative Medicine was also established in 1998 [6].

Patients often use CAM based on information from the mass media, family, and friends. However, CAM may damage health [7]; therefore, communication with Western medicine physicians is necessary for patient safety. Communication between patients and medical professionals regarding CAM is rare because of fear that the effects of CAM will be refuted [8,9]; however, these studies failed to sufficiently perform deep psychological analyses to clarify the factors that affect patients. NCCIH has implemented a campaign called "Time to Talk" to raise awareness among patients and physicians as well as to develop patient education programs related to communication [1,10,11].

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The following two issues are primarily considered when examining patient–physician communication regarding CAM use in Japan. First, some CAM therapies have been used for a long time; thus, they have a more amenable cultural background and social foundation. The unique systematized *Kampo* medicine practiced in Japan includes herbal medicine and acupuncture, thereby facilitating cultural acceptance [12]. Furthermore, in 2010, the Japanese government issued a policy to promote “integrative medicine” combining Western medicine and CAM; an investigation has been launched into the current state of integrative medicine [13]. The second issue is the distinctive communication style of Japanese people, characterized by “reservation” and “conjecture,” with little self-assertion or self-expression [14].

Many previous studies of CAM in Japan have investigated its effectiveness and safety, but limited research has been conducted on poor patient–physician communication regarding CAM [15,16]. Moreover, studies on patient–physician communication have focused on health literacy (HL) as a means of determining the health information and health status knowledge of patients and as a skill for improving communication ability. The World Health Organization (WHO) defines HL as “the cognitive and social skill which determines the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health” [17]. HL consists of three subscales: functional, communicative, and critical skills [18]. Previous studies have investigated the relationship between CAM use and functional HL or education [19,20]. However, no studies have investigated the relationship between communication regarding CAM and communicative and critical HL. In Japan, writing and reading skills are high and communicative and critical skills are considered important. Therefore, it is necessary to investigate the relationship between patient–physician communication regarding CAM and communicative and critical HL.

The aim of the present study was to investigate CAM disclosure in Japanese patients with chronic disease, and examine the relationship of patient HL with patient–physician communication with regard to CAM. In this study, we used the broad definition of CAM as “all measures undertaken by patients to treat their illness and improve, maintain, and enhance their physical condition in addition to treatment received at hospitals practicing Western medicine.”

2. Study design

The data were gathered in two stages as follows:

Study 1: The first stage involved semi-structured interviews with 35 chronic disease patients who were identified using snowball sampling. The results from the interviews then formed the basis for questions in the questionnaire, in addition to information obtained from a review of previous studies [21].

Study 2: The questionnaire was then sent to 920 participants sampled through 14 patient associations (Japan Parkinson’s disease Association, Japan Spino-Cerebellar Degeneration/Multiple System Atrophy Association, Japan Connective Tissue disease Association, Japan Behcet’s disease Association, Keyaki-kai, etc.). It is important to provide this information at the beginning of this section as it gives the reader a more structured picture about the study design and the sampling processes.

3. Study 1-Interview

3.1. Participants and procedures

To identify the attitudes and reasons related to patient–physician communication regarding CAM based on patient narratives, we performed interviews with 35 chronic disease

patients who used CAM at facilities for patients (Kumamoto Intractable disease Consultation & Support Center, etc.) between December 2010 and January 2011, using snowball sampling. The semi-structured interview consisted of questions about whether patients discussed CAM usage with their physicians and reasons for not disclosing this information. The analysis of the interview data involved coding and categorizing the content following repeated readings of the transcripts and field notes to understand the overall content, according to the method developed by Lofland et al. [22]. To improve the validity of the analysis, we performed member checking with the survey participants and a peer examination with research collaborators.

3.2. Results

Thirty-five patients consisted of 9 men (25.7%) and 26 women, with a mean age of 53.4 years. Their conditions included the following: musculoskeletal diseases, rheumatic diseases, cancer, ocular and neuromuscular diseases. Patients had used supplements, health food, massage, and various other CAM therapies (refer to Fig. 1). The reasons not to disclose CAM to physicians included lack of physician understanding, fear of angering the physician, reticence to discuss this issue, and no time to discuss CAM.

“I cannot tell my doctor. If I do tell, he will say that herbal medicine would not work for rheumatism, and condemn me.” (70s, rheumatic disease, female)

“My doctor’s consultation lasts for approximately two minutes. I am also fine with this to some extent, so I do not have time to talk about CAM.” (60s, Ossification of posterior longitudinal ligament, female)

“Previously, a doctor told me that, “No matter what treatment you try for your disease, you will not heal.” (40s, Systemic lupus erythematosus, female)

“My doctor is a very scientific and theoretical person. I wanted to be a good patient for him. I like his work.” (50s, Lymphocytic leukemia, female)

“I knew my doctor did not believe in Kampo. Since I was drinking it, I felt very guilty.” (30s, Idiopathic thrombocytopenic purpura, female)

4. Study 2-Survey

4.1. Materials and methods

4.1.1. Participants

The self-administered questionnaire was created based on previous studies [5,8] and results of the above interviews. After a pre-test to 20 patients and modifications, a self-administered questionnaire survey was conducted between May and July 2011 involving 920 patients with chronic diseases who were aged ≥ 20 years. We requested the cooperation of 16 patient associations, using snowball sampling and Google search; 14 patient associations approved it. Patients with physical and mental burden due to being very old or of poor health were excluded from the sample. Among the questionnaires distributed from the patient associations to the patient’s home by post, 603 were returned (response rate = 65.0%); eight were excluded because the respondent was not ill, and 25 were excluded due to >20% missing answers. Of the remaining 570 questionnaires, 428 were completed by participants who had used CAM for >10 years; these were subjected to analysis.

The Ethics Committee of the Graduate School of Medicine, the University of Tokyo (approval numbers: 3263, 3394) approved the studies.

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