# RESEARCH ARTICLE

# Lay Beliefs, Knowledge, and Attitudes Towards Cancer: a Pilot Study in Japan

# Miyako Tsuchiya

#### **Abstract**

Background: The attendance rates for cancer screening are low in Japan. Little is actually known about how the Japanese perceive cancer. Since beliefs about illness affect individuals' health care practice, the aim of this study was to explore beliefs about cancer and factors associated with those beliefs, focusing on representative cancer sites. Materials and Methods: Japanese adults (≥20 years old) who had not been diagnosed with any cancers and were not health care professionals were recruited, using a convenience sampling approach. A total of 91 participants completed questionnaires including open-ended questions. Thematic analysis was used to analyze the responses. Results: Five themes were suggested: (i) a threatening illness that might greatly change one's future life; (ii) basic cancer knowledge; (iii) a curable illness with early detection and adequate treatment; (iv) causes of cancer; and (v) anyone can develop cancer. Families or friends' negative consequences of cancer were associated with negative beliefs about the disease. Gestational cancer was the most representative site of most themes. Conclusions: A threatening illness (e.g., death or incurable illness) was the most common belief among the Japanese laypeople. Importance of early detection and treatments should be more emphasized, and future screening programs should include strategies modifying negative cancer beliefs among Japanese laypeople.

Keywords: Cancer - factors - Japanese - perception - open-ended questions - thematic analysis

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# Introduction

Lay beliefs about illnesses are often generated through personal or significant others' experiences, through culture, or via the media (Morrison and Bennett, 2006). These beliefs usually differ from health care professionals' bio-physiological explanations used in clinical settings (Dein, 2004) or from actual patients' beliefs (Chambers et al., 2012). Previous research among Asian people has revealed several beliefs about cancer. For example, the word cancer itself arouses fear among Filipinos in the United States because they immediately link it with the terminal phase of cancer (Wu and Bancroft, 2006). In contrast, Malaysian women have reported that early detection and adequate treatments can cure cervical cancer (Baskaran et al., 2013). In terms of beliefs in causes of cancer, fatalism (god's decisions), bad luck, karma (misconduct in a previous life) or contagion have been widely reported among South Asian women and Chinese people in Australia (Kwok and Sullivan, 2006; Wei et al., 2013; Wang et al., 2014; Das et al., 2015).

Such lay beliefs seem to be powerful determinants of one's health care practice. For example, Honda and Gorin (2005), who conducted a survey study among asymptomatic Japanese Americans, reported that participants whose families had developed colorectal cancer tended to fear a cancer diagnosis and, consequently,

did not undergo colorectal cancer screening. Besides, more than 50% of the participants had lived in the United States for over 17 years, a period associated with high acculturation (Abraido-Lanza et al., 2005). Since one's perceptions are influenced by culture (Applegate and Sypher, 1988), Honda and Gorin's findings might differ from those among indigenous Japanese people. Careful review of the literature revealed only one study investigating indigenous Japanese people's cancer perceptions: Takahashi et al. (2012) conducted an Internet survey about perceptions of cancer incidence rates and five-year survival rates in Japan. They found that participants believed the incidence of cancer to be lower than in the epidemiological fact. Although these researchers significantly contributed to revealing gaps between lay perceptions of cancer and epidemiological facts, indigenous Japanese people's beliefs about cancer, other than incidence and survival rates, are still unclear.

In Japan, approximately 805,000 people were estimated to develop cancer in 2010 (Matsuda et al., 2013). For both genders, gestational cancer, lung cancer, and colon cancer have high incidence rates (Matsuda et al., 2013). Around 365,000 people died from cancer in 2013 the highest cause of mortality, followed by heart disease. In an order similar to the prevalence for both genders, lung, gestational, and colon cancer have high mortality rates (Matsuda et al., 2013). A free screening program

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for gestational, lung, colon, breast (40-69 years old), and cervical cancer (20-69 years old) has been legislated, and those eligible can be screened at their local health centers. However, the attendance rates of these screening programs are very low: gestational, 39.6%; lung, 42.3%; colon, 37.9%; breast, 43.4%; and cervical, 42.1% (Ministry of Health, Labour and Welfare, 2013). Therefore, to develop an effective strategy for enhancing Japanese people's health care practice, it is worthwhile to explore their beliefs about cancer. Specifically, with open-ended questions, this study explores Japanese laypeople's beliefs about cancer, the factors associated with those beliefs, and representative cancer sites for the beliefs.

# **Materials and Methods**

#### Procedure

Inclusion criteria for this study included the following: Japanese adults (≥20 years old), who are not previously diagnosed with cancer and who are not health care professionals. To recruit potential participants, community centers, parent-teacher associations, and alumni societies were conveniently selected and approached via letters or emails. After these organizations' gatekeepers agreed, questionnaires were distributed to their members (N=161) via the gatekeepers. For the participants' convenience, electronic versions and Web questionnaires were also available. The nature of the study, confidentiality, anonymity, and how to obtain consent were explained in the informational letters. Returning completed questionnaires evidenced the participants' agreement to participate in the study. A total of 91 participants returned completed questionnaires (response rate, 56.5%).

#### Measurement

Self-report questionnaires included two open-ended questions about images of cancer. The statements were: "Tell us what you think when you hear the word cancer" and "Tell us what made you conceive of cancer as you described in the previous response." Each participant was allowed to write more than one response. Following these questions, participants were asked to choose, from a provided list, the cancer they most associated with their image of the disease: gestational, hematologic, colon, prostate, ovarian, pancreatic, cervical, lung, breast, brain tumors, liver, or other. Questions about participants' characteristics (gender, age, marital status, educational levels achieved, occupation, living areas, and cohabitants) were also included. In this study, data relevant to participants' cancer images were analyzed and reported.

# Analysis

Descriptive analyses (means, standard deviations, and frequencies) were performed on the participants' characteristics. Responses to the open-ended questions were analyzed using a thematic analysis (Boyatzis, 1998) with a coding unit determined to be a phrase. Mutual exclusivities were ensured using a coding book; similar labels were combined to make categories. Whenever necessary, a category's definition was modified. Themes reflecting participants' cancer images and their influential

factors were identified. To confirm the consistency of this analytic process, one month later, the author performed another data analysis using exactly the same procedure as that mentioned above. Additionally, the relationships between cancer-image themes and influential factors and between the cancer described and the cancer image were identified by using a matrix. Frequencies and percentages for participants were calculated.

#### **Results**

Participants' characteristics

The mean age of participants was 47.9 years old (SD=18.89). More than half the participants were female (62.6%). Most participants (72.5%) were married, and over 80% had completed higher education. Nearly half the participants (44.0%) had paid jobs. Most participants (88.0%) lived in cosmopolitan cities in Japan.

## Cancer images

A thematic analysis suggested five main themes and 15 subcategories, relating to beliefs, knowledge and attitudes towards cancer. The 5 main themes were (i) a threatening illness that might greatly change one's future life (8 subcategories: death, an incurable disease, long and severe cancer therapy, uncertainty of cancer treatments' efficacy, psycho-economic impacts on patients and their families, serious disease, aversive physical affects due to cancer's progression, and a threatening disease); (ii) basic cancer knowledge (3 subcategories: cancer treatments, cancer prevalence in Japan, and cancer mortality in Japan); (iii) a curable illness with early detection and appropriate treatments (2 subcategories: cure by early detection and cure by early and appropriate treatments); (iv) causes of cancer (1 subcategory: causes of cancer); and (v) anyone can develop cancer (1 subcategory: anyone can develop cancer). Table 1 summarizes the participants' frequencies and percentages for each subcategory.

Theme 1: A threatening illness that might greatly change one's future life. This theme was defined as beliefs that evoked participants' fear and worries due to cancer's incurable nature. The majority of participants' responses were categorized under this theme. As Table 1 demonstrates, this theme includes the general cancer image of a serious disease and threatening disease, and most subcategories were relevant to the physical impacts of cancer.

Cancer equals death was the most dominant belief (33.0%), with incurable disease second (27.5%). Long and severe cancer therapy was third (14.3%), and in this subcategory, the side effects of chemotherapy was often cited. Approximately 12% of the participants reported the uncertainty of cancer treatments' efficacy, and in this subcategory the susceptibility of cancer treatments and death or life depends on ones' fate was cited. Approximately 8% of the participants reported aversive physical effects due to cancer's progression. In this subcategory, pain and prostration in the terminal phase was cited.

Besides these physical impacts, one subcategory

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represented psychological and financial issues among patients and their families (12.1%). In this subcategory, 'Cancer-the illness that shocks people the most when they hear they have it and not only to patients, but also to their families, cancer is a financial burden' was reported. Some participants that anticipated developing cancer: 'worried about what would happen to their families'.

Theme 2: Basic cancer knowledge. This theme was defined as knowledge about cancer and the situation in Japan, not evoking the feeling of fear and worries in the participants. As Table 1 shows, cancer treatments were the most dominant subcategory (9.9%). This subcategory included surgery, radiotherapy, stage, side effects of treatments, and second opinions. The second most dominant was cancer prevalence in Japan (8.8%). In this subcategory, 'one of the three major diseases among Japanese people; prevalence has been increasing; and one in two Japanese people develop cancer in their lives' were reported. Fewer participants (4.4%) reported cancer mortality in Japan. In this subcategory, 'the highest mortality rate and among diseases that Japanese people develop, [cancer] has the highest possibility of death' were cited.

Theme 3: A curable illness with early detection and appropriate treatments. This theme was defined as beliefs about the importance of early detection and appropriate treatments for cure. As Table 1 shows, cure by early detection was the most dominant (14.3%). In this subcategory, it was said that 'cancer was an incurable disease in the past, but I feel that [developing cancer] no longer worries us if it is diagnosed at a very early stage and the importance of regular check-ups' was included. The other subcategory was cure by early and appropriate treatments, which had a lower percentage (4.4%) than that of early detection.

<u>Theme 4</u>: <u>Causes of cancer</u>. This theme was defined as beliefs about causes of cancer, and about 8% of responses

were categorized under it. In this theme, heredity, lifestyles including smoking, stress, unclear causes, and personality were cited. In terms of personality, a participant reported, 'I feel that people who develop cancer are more likely to anger easily and constantly be irritated'.

Theme 5: <u>Anyone can develop cancer</u>. This theme was defined as beliefs about whether participants were likely to develop any cancers in their lives. About 8% of responses were categorized under this theme, including 'advancing age brings [cancer] closer to me'.

Influential factors on cancer images

Three themes-families and friends' experiences of cancer, media, and no special reasons-were extracted. Participants whose families or friends had developed cancer (n=65) reported cancer equals death (35.4%) and an incurable disease (24.6%). Following these two subcategories, the uncertainty of cancer treatments' efficacy was reported (15.4%). In contrast, approximately 14% of participants reported cure by early detection. The qualitative data suggested that the survival or the death of a participant's family member or friend affected these negative and positive beliefs; for example, a participant who perceived cancer as an incurable disease reported that 'because people surrounding me and friends who had developed cancer never recovered from it'. In contrast, a participant who perceived that cancer could be cured by early detection and early appropriate treatments reported, 'My relative died from lung cancer, but my friend who developed colon cancer recovered because it was diagnosed so early'. Moreover, around 11% of participants reported that cancer was anyone can develop cancer.

Participants who had been influenced by media (n=8) reported cancer equals death (62.5%), aversive physical affects due to cancer's progression (62.5%), an incurable disease (37.5%), long and severe cancer therapy (37.5%), and psycho-economic impact on patients and their families (37.5%). The qualitative data suggested that the media might affect these perceptions; for example, participants

Table 1. Frequencies of Responses in Themes and Subcategories

Themes	Subcategories		Participants (N=91)
		N	
Threatening illness	Death	30	33.0
	Incurable disease	25	27.5
	Long and severe cancer therapy	13	14.3
	Uncertainty of cancer treatments' efficacy	11	12.1
	Psycho-economic impacts on patients and their families	11	12.1
	Serious disease	7	7.7
	Aversive physical affects due to cancer's progression	7	7.7
	Threatening disease	6	6.6
Basic cancer knowledge	Cancer treatment	9	9.9
	Cancer prevalence in Japan	8	8.8
	Cancer mortality in Japan	4	4.4
Curable illness	Cure by early detection	13	14.3
	Cure by early and appropriate treatments	4	4.4
Causes of cancer	Causes of cancer	7	7.7
Anyone can develop cancer	Anyone can develop cancer	7	7.7

<sup>%,</sup> percentage. Threatening illness; a threatening illness that might greatly change one's future life; curable illness; a curable illness with early detection and appropriate treatmentss

who perceived that cancer was associated with severe side effects of treatments reported, '[This was] because I have watched a documentary about cancer patients on a TV program'. None reported that 'anyone can develop cancer'.

Participants who did not report any specific reasons (n=25) reported that cancer was an incurable disease (36.0%), cancer equals death (28.0%), and would need long and severe cancer therapy (20.0%). None reported that cancer was anyone can develop cancer.

Cancer images and cancer sites

Regarding Theme 1 (a threatening illness that might greatly change one's future life), gestational cancer was most representative of several subcategories (i.e., 46.7% for death, 28.0% for an incurable disease, 30.8% for long and severe cancer therapy, 45.5% for psycho-economic impacts on patients and their families, 42.9% for aversive physical affects due to cancer's progression, and 66.7% for a threatening disease). Regarding Theme 2 (basic cancer knowledge), gestational cancer was the most representative of cancer prevalence in Japan (50.0%). Gestational, colon, pancreatic, and lung cancer were the most representative of cancer mortality in Japan (25.5%, respectively). Regarding Theme 3 (a curable illness with early detection and appropriate treatments), gestational cancer was the most representative of cure by early detection (30.8%) and cure by early treatments (50.0%). Colon, cervical, lung, and breast cancer were the second most representative of cure by early detection (15.4%, respectively). Regarding Theme 4 (causes of cancer), gestational cancer was the most representative (57.1%). Regarding Theme 5 (anyone can develop cancer), colon cancer was the most representative (28.6%). Gestational, cervical, lung, and breast cancer were the second most representative (14.3%, respectively).

#### **Discussion**

Using open-ended questions, this pilot study explored Japanese laypeople's beliefs about cancer, its influential factors, and representative cancer sites. Regarding cancer beliefs, the most dominant theme was related to negative physical and psycho-economic impacts of cancer. For this study's participants, cancer appeared to be associated with fear. This was consistent with the findings among Filipinos in the United States (Wu et al., 2006). As Baskaran et al. (2013) reported the importance of early detection and adequate treatments were also reported in the current study. However, the percentage of participants with these beliefs was lower (14.3% and 4.4%, respectively) than that of cancer equals death and an incurable disease (33.0% and 27.5%, respectively).

As causes of cancer, supernatural explanations (e.g., fatalism, bad luck, karma) were not reported in the current study; this was inconsistent with several studies among Asian women (Kwok and Sullivan, 2006; Wei et al., 2013; Wang et al., 2014; Das et al., 2015). Fatalism, bad luck, and karma are closely tied to religions that are often the center of human mentality and everyday life (Kwok et al., 2006). However, the Japanese do not generally believe

in any specific religion (Tazaki et al., 2002) so that biophysiological explanations, such as heredity and lifestyle, rather than religion-related explanations, might have been more frequently reported in the current study.

Unexpectedly, only a few participants (7.7%) reported the possibility of developing cancer. This percentage might be reasonable because only 8.8% of participants acknowledged high cancer prevalence rates in Japan. This attitude toward cancer, however, might be problematic when considering the health care practice; according to social cognition models (e.g., the theory of planned behavior [Ajzen, 1991]), low perception of susceptibility to developing cancer might predict poor behavioral intention and behaviors, for example, screening attendance. Moderate associations have been empirically reported among Korean population (Kim et al., 2014).

In this study, beliefs about cancer were closely related to participants' families' or friends' experiences of cancer, the media, or not special sources. Participants whose families or friends had developed cancer tended to report negative cancer images. Some previous research has reported that gaps between lay perceptions and epidemiological facts were affected by education (Alexandraki and Mooradian, 2010; Banning, 2011; Reis et al., 2012), whereas the current sample included more than 80% who had completed higher education. Instead, personal experiences of a loved one-the death of a family member or friend-might have significantly affected participants' perceptions in the current study.

Regarding representative sites of reported cancer images, gestational cancer was associated with most themes. This finding seems to reflect the epidemiological facts of cancer in Japan; gestational cancer has the highest prevalence rate and the second highest mortality rate for both genders (Matsuda et al., 2013). Gestational cancer was also a representative of *cure by early detection and cure by early and appropriate treatments*, followed by colon, cervical, lung, and breast cancer. For these cancer sites, free screening programs have been provided, and the results indicate that participants know that screening programs are effective in minimizing the effects of cancer.

As far as the author knows, this is the first study to explore Japanese laypeople's beliefs and attitudes about cancer. However, there were several limitations. As the present study was a pilot, the sample size was small. Because convenience sampling was used, the sample was not a representative of Japanese laypeople. Thus, the findings cannot be generalized. Open-ended questions were used to explore beliefs about cancer, but this method might be difficult for people who had never thought about cancer; also, it might be difficult for participants to express all their beliefs in writing. Perhaps, this situation led to less than full development of two themes (causes of cancer and anyone can develop cancer). A larger-scale quantitative study is required to confirm this study's findings. Moreover, associations between Japanese laypeople's beliefs about cancer and their screening attendance behavior, especially for gestational cancer, need further study.

In summary, the current study mainly explored Japanese laypeople's perceptions toward cancer, using

open-ended questions. *Threatening illness* was the most common belief among the Japanese laypeople. This belief seemed associated with gestational cancer, which is highly prevalent for both genders, but the screening attendance rate was low in Japan. These findings may be useful for researchers or the government to develop a useful strategy modifying Japanese people's negative cancer beliefs and facilitating screening attendance behavior.

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