Japanese cancer patients’ participation and satisfaction with treatment related decision making with doctors: a qualitative study

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Abstract

Background

As is the case in many western countries, the current trend in Japan is to respect patients’ autonomy regarding treatment decision-making. Although growing interest and advocacy regarding informed consent has been reflected in research on Japanese cancer survivors’ attitudes toward treatment decision making, there has been little investigation regarding how cancer survivors themselves evaluate their involvement in the decision making process. The purpose of this study was to identify and describe the relationship between levels of participation and satisfaction with treatment related decision-making processes of cancer patients.

Methods

Qualitative analysis of data from semi-structured interviews with 24 Japanese patients was conducted.

Results

The decision making styles were classified into five types based on their level of participation and satisfaction with the overall process: patient-initiative, forced self-decision, resigned, selective doctor-initiative, and doctor entrusting. The patient-initiative type wanted to actively participate in decision making surrounding their treatment and felt highly satisfied regarding their participations in the process. The forced self-decision type felt they were forced into treatment decisions by doctors even though they lacked sufficient information and experience to make rational decisions, and subsequently this group experienced low satisfaction with their participation. The resigned type thought they had no choice but to trust their doctor’s advice because of the wide information gap in medical knowledge between patients
and doctors; also resulting in low satisfaction. The selective doctor-initiative type wanted to be informed as much as possible about available treatments, however, they respected their doctors’ expertise and thus expected them to make the final decisions; and this group was satisfied with their doctor’s initiative. The doctor entrusting type considered the doctors’ decisions unquestionably, and were highly content to trust the decisions made without their active participation.

**Conclusions**

Doctors should consider the fact that patients’ express individuality in their desire for participation, thus always encouraging involvement will not satisfy all patients.
Background

Cancer is a common and potentially life-threatening illness, which has been the leading cause of death for adults in Japan since 1984 [1]. As a result of developments in diagnostic and treatment methods, patients have greater chances of survival with longer lengths of life after diagnosis. Cancer patients face several critical decisions regarding their treatment options which have significant impacts on their quality of life and potential for length of life. Making difficult decisions based on the understanding of complex medical information is a key factor in a patient’s length of survival and quality of life.

Over the last two decades, in oncology and other medical fields, patient participation in treatment related decision-making has been promoted as ethically and clinically desirable [2-4]. Patients with cancer and other chronic diseases have largely come to expect to participate in treatment decision-making which reflects their own wishes and values [5-7].

A number of studies have demonstrated a correlation between patient participation preferences in treatment decision-making with patient characteristics such as a patient’s age, gender, education, type of disease, and disease severity [8-16]. Several studies have pointed out that patient participation in medical decision-making has a positive influence on health outcomes, increasing satisfaction in medical care received as well as promoting patient autonomy [17-19].
The sharing of information between doctors and their patients is an important factor indicating patient participation. It has been suggested that in order to promote shared decision-making, doctors need to be more willing to present information regarding treatments [7]. Recently, to facilitate doctor patient communication, evaluation techniques which allow the analysis of doctor-patient interaction have been developed [20]. Other researchers have assessed communicative styles and information seeking behaviors among patients [21, 22]. For example, Street [22] suggested that patients who are more assertive and who ask more questions acquire more information from their doctors than those who are less verbal.

Consistent with developments in Western countries, in Japan, the concept of patient autonomy and shared decision making have come to be widely recognized [23-26]. While the diagnosis of life-threatening illness was not often disclosed to patients in the past [27], recent surveys with health professionals and cancer survivors in Japan have revealed respondents’ tendency to prefer cancer diagnosis disclosure and an increase in the level of expectation that patients will participate in treatment decision making processes [28-32].

Since the 1970s, the concept of shared decision-making has become an established part of treatment practice in Western countries. Previous studies have defined participation in decision making as taking into account the views of the parties involved in the final decision making (focusing on the actors) [11], while other research points out that shared decision making is based on information exchange of the doctor’s medical knowledge and patient’s values are followed by arrival at mutual agreement (focusing on the process) [5, 33, 34].
Although growing interest and advocacy regarding patient participation has been observed in Japan, due to differing cultural contexts regarding patient autonomy, consumer participation and health insurance systems, there is some doubt whether the concept of shared decision making which has been developed in western counties will be directly applicable to the situation in Japan. Therefore it is crucial to explore Japanese patients’ views on participating in treatment decision making. There has been little investigation on the level of involvement and evaluation of patient participation in treatment decision amongst cancer survivors in Japan [35, 36]. Thus, this study aimed to investigate the relationship between the level of participation and satisfaction in overall decision making process from Japanese patient perspectives.

**Methods**

A qualitative approach was taken in order to explore Japanese cancer patients’ experiences relating to treatment decision-making. Due to the lack of research about treatment decision-making patterns in Japan, the authors decided to conduct semi-structured interviews with cancer survivors to obtain detailed descriptions on the variety of experiences and views with regards to participation in treatment decision-making.

**Recruitment of interview respondents**

The authors attended the meeting of a self-help group of cancer survivors in the Tokyo Metropolitan area, explained the purpose and the procedures of the research, and asked members to participate in being interviewed. Besides this, the authors
participated in attending the regular monthly meetings of the group over 10 months, in order to gain an understanding of the background issues faced by cancer survivors. All ethical considerations were explained, including respondents’ voluntary participation and ability to withdraw from the study at any time, assurance that the data would not be used for other purposes and that all information would be kept strictly confidential. Participants who chose to participate were asked to contact the principal researcher, at which time a convenient time and place to carry out the interview was negotiated.

**Data collection**

After obtaining verbal informed consent, semi-structured interviews were conducted by the primary author. Interviews were conducted at a place chosen by respondents that would protect participants’ privacy and create a comfortable atmosphere for discussion such as respondents’ homes, community centers, coffee-shops, and hospital waiting areas. The interviewees were given a book coupon for 1000 yen (about US $9.00) for their participation. With permission, all the interviews except one were tape recorded. For the interviewee who declined tape recording, the interviewer made interview notes copying informant’s words as precisely as possible and this data was used as supplementary data for analysis. The interviews lasted 80 minutes on average, ranging between 55 to 200 minutes, and a total of 35 hours of interview data was collected.

During the interviews, informants were asked about their experiences regarding their diagnosis with cancer and in making treatment related decisions, the type and amount of information about cancer and treatment options that was provided by their doctor,
the process and overall satisfaction of their treatment decision-making process, and
their perception of the doctor-patient relationship. As for treatment related decisions,
informants were asked about their experiences regarding critical treatment such as a
surgical operations, radiation therapy, and chemotherapy. Informants were asked
questions about basic demographic information including gender, age, level of
education, and cancer type. Immediately after the interview, the interviewer wrote
field notes recording impressions of each interview.

Data analysis
All tape-recorded interviews were transcribed verbatim. Following the data analysis
method by Lofland and Lofland [37] repetitive transcript reading was conducted and
followed by the construction of multiple codes that were grouped together into more
conceptualized categories. Multiple codes were compared according to their
similarities and differences, then, similar codes were grouped together into categories.
Categories were developed in order to explain the variety of decision making styles
that informants described. One of the authors (YW) conducted the initial analysis.
Then all authors scrutinized the preliminary categories to check if the categories
represented the experiences found in all interviews. After the authors reached
consensus, the results were sent to two of the informants for feedback and to validate
the researcher’s analysis of the categories [38]. The informant feedback indicated
satisfaction that the categories developed by the researchers adequately explained
respondent experiences.

Results
A total of 24 interviews were conducted with 10 men and 14 women. Informants’
background information is presented in Table1. The informants’ mean age was 57.8 years (range 36 to 78 years) and median length from diagnosis at interview was 5 years (range 6 months to 17 years). The primary location of the informants’ cancers were the lung, esophagus, breast, pancreas, liver, stomach, uterus, colon, prostate, cartilaginous tissue, and lymph nodes. Two had multiple cancers and 6 were recurrent.

The data was categorized according to the informants’ perceived level of participation in treatment decision-making and the level of their satisfaction with the overall decision making process. Informant’ involvement in decision-making was determined by the existence of behaviors such as information seeking, questioning their doctors and expression of their treatment preferences.

Figure 1 shows the five types of decision-making patterns that emerged from the analysis of the interview data; which included the ‘patient-initiative’, ‘forced self-decision’, ‘resigned’, ‘selective doctor-initiative’, and ‘doctor entrusting’ types.

**Patient-initiative type**

The informants in this category showed both a high level of involvement in decision-making and a high level of satisfaction in doing so. They had their own opinions, beliefs, and values with regards to their treatment:

> I have my own philosophy that doctors treat diseases but they don’t aim necessarily to keep us alive. I know many people who have died even after following everything their doctors recommended. Why don’t patients participate in their own treatment decision-making?
They should. I believed the only way to survive was to be involved in making decisions about my treatments. (Informant O)

This informant had a strong belief in his own self-determination and appealed strongly to his doctor to respect his preferences, rejecting oral chemotherapy drugs because he did not believe in the drugs efficacy.

Informants in this category had high self-confidence in their knowledge of their medical condition and treatment options. They believed that patients should take a strong initiative in decision making and gathered as much information as possible in order to reach their own conclusions. Thus doctors were seen as consultants with special knowledge and skills with whom these patients could utilize as important sources of information. These patients were satisfied in being left to make treatment decisions and were pleased when their doctors respected their preferences and treated them as an equal partner of decision making. They were very satisfied with the decision-making process.

**Forced self-decision type**

The second category was the forced self-decision type in which informants showed a high level of involvement in decision-making but experienced a low level of satisfaction in doing so. They were directed or forced to choose particular treatments while feeling that they did not have enough information or understanding of their medical condition and treatment options. Although they participated in deciding which treatment to undertake, their recollection of the decision making process was very negative and these informants felt that the responsibility for decision-making
was imposed on them by their doctors. As one informant stated:

At the time of making the decision regarding which treatment to undertake, I had to choose something and give my doctor an answer. It was not something you could satisfactorily call “shared decision-making”. I felt I had to reach a conclusion despite my lack of medical knowledge. Perhaps I did take part actively in the process, because I chose one treatment out of the options that were given to me, but I don’t think it was a real participation. It was just a case of an ignorant person being forced to make a decision. (Informant I)

Informants in this category were extremely perplexed at being told to decide by themselves. Some were intimidated because there was a lack of enough time and information to make a final decision, and others were disconcerted because they wanted doctors to take initiative.

I didn’t want to decide by myself, but he (the doctor) told me I was the decision maker. This troubled me, and from then on I couldn’t sleep well. I wish the doctor had made the decision for me. I wanted the doctor to lead me in the right direction. I was totally confused, because the doctor imposed decision making on me. (Informant R)

**Resigned type**

The third category was the resigned type in which informants showed both a low level of involvement in decision-making with a low level of satisfaction in doing so.
Although they actually wanted to participate in decision making, they gave up on the idea because they recognized that a wide information gap in medical knowledge existed between them and their doctors. Therefore, when their doctors chose certain treatment for them without providing other treatment options or giving them a chance to express their preferences, they thought they could not help but be resigned to entrusting their doctors to make the best decision for them.

For example, informant K remarked:

I can’t say I was satisfied with the decision-making process, but I thought I couldn’t help but accept what my doctor said. As a patient, I thought there was nothing I could do about it… even though I wanted to participate in deciding my treatment. If the doctor had given me information about treatment options I think I could have chosen one. The doctor should have automatically explained to me what the best option was, as well as providing reasons and explaining other options. (Informant K)

Another informant in this category said:

Doctors often bring up the idea of informed consent as if they respect patients’ will, but in fact they are persuasive of their idea and force their opinions on patients. That’s the way doctors are, I think. (Informant D)

**Selective doctor initiative type**

The fourth category was the selective doctor-initiative type in which informants
showed a high level of satisfaction and but whose level of participation in decision-making was relatively low, falling between the patient initiative type and the doctor entrusting type. The patients in this category, like the patient-initiative type, have their own opinions, beliefs, and values with regards to their treatment and the choice of their doctor. They want to be informed as much as possible about the treatment options. However, this group diverges from the patient initiative type in that they expected doctors to make the final decisions. Another difference observed in both this group and the resigned type is that they actively, not reluctantly, transferred the power of decision-making to doctors in whom they entrusted and they are quite satisfied to do so, as illustrated by an informant who states:

I first asked my doctor for his opinion and then gathered lots of information from the media, the internet and so on to find information that endorsed his opinion. Because doctors possess various data and clinical experience, I doubted that it was really necessary for me to make the final decision. I trusted my doctor. The ultimate purpose was to cure my disease, not to decide my treatment by myself. The fact that the treatment is chosen by the patient doesn’t guarantee its effectiveness. If you understood the treatment and agreed, it doesn’t matter who made the decision. Therefore it is perhaps reasonable to say that ‘active participation’ can be rephrased as ‘active agreement’. (Informant B)

The individuals in this group might seem to have a low level of participation because their treatment decisions are basically made by their doctors; however, their
satisfaction in the decision-making process is high because they trust their doctors and their decisions. Informants in this group were also eager to gather information on the quality of hospitals and doctors. The purpose of collecting information was not to empower themselves to make treatment decisions but rather to choose the right doctor, or to endorse the doctor’s advice and understand it more thoroughly. In other words, the decision-making process for those in this category means choosing or being allocated a doctor whom they can trust enough to make the right decision for them. Although they do not choose the final treatment, they maintain a sense of self-determination during the course of the treatment decision-making by choosing their doctor by themselves or having a doctor who they are satisfied with to make treatment decisions on their behalf.

**Doctor entrusting type**

The last category of participant types was the doctor entrusting type in which informants showed a low level of involvement in decision-making and a high level of satisfaction in doing so. These informants perceived that doctors should take the initiative in medical decision-making and the patients’ role is to accept these decisions unquestioningly. Like the selective doctor-initiative type, those in this group see doctors as proxy decision makers for their treatment options. However, this type differs from the selective doctor-initiative type in that they believe in and trust the doctor’s professionalism in general and do not feel the need to evaluate the quality of each doctor or to understand the content of the advice provided. These informants also differed from the resigned type in that they seeming willing to not participate in decision making. Although, like the resigned type, they recognized the information gap between doctors and patients, they actively expected doctors, as specialists, to act
as the final decision maker. They are willing to accept recommendations from their doctors, and are therefore quite satisfied with the decision-making process. As one informant states:

> Basically, I trust doctors. In general, doctors, like lawyers, have a strong philosophy on life, so I respect them. My doctor only explained to me that there would be no problems if I had the operation he recommended. I couldn’t say anything to him because of my lack of knowledge. Therefore, because he said it would be all right, I trusted him and didn’t talk to him further much about the treatment. I placed my complete trust in him from then on. (Informant T)

**Change of a decision making style**

Although we have categorized the data from the Japanese cancer survivors’ interviews into five types of decision making styles, in practice, informants’ comments revealed that these categories are not fixed for them and that these decision making styles can change under different conditions in the course of the disease. Informant I who was categorized as a patient-initiative type at the interview, stated that he had gradually developed into the patient-initiative style after his confusion at the initial treatment phase when he was forced to make treatment decisions without enough knowledge. He felt as though his doctor had shifted responsibility for treatment decision making onto him, despite his unwillingness. After this experience informant I said he became to realize the importance of sharing responsibility with his doctor, and became more assertive in asking his doctor for explanations about his disease and treatments and to
gather information from other sources to understand what the doctor said. His awareness of patients’ rights and his role in making decisions with his doctor changed from the forced self-decision type to the patient-initiative type.

At the first hospital, nobody told me what my disease was. Well, at the next hospital, the doctor told me about the details of my disease, but he compelled me to make crucial decisions that would ultimately kill or cure, despite very little knowledge about the disease. I experienced many, many problems, which made me change the way I participate in decision making. ...A patient must judge if the doctor is saying the right thing or not, by him/herself. That is why I asked another hospital for a second opinion...If you want to make your own choice, you must have knowledge. So, I investigated, sought information, and asked questions. I challenged myself to listen to people who had different ideas on treatment and read books written by them. Then, I chose the doctor who gave me convincing answers to my questions. That is what I call participating in a decision making process. (Informant I)

**Discussion**

This study categorized Japanese cancer survivors’ decision making styles into five types based on their levels of participation in treatment decision-making and their overall satisfaction with the decision-making process: patient-initiative, forced self-decision, resigned, selective doctor-initiative, and doctor entrusting. While the
importance of respecting patient autonomy and promoting patients’ involvement in treatment related decision-making processes has been widely recognized in many countries [2, 3, 39, 40] as well as Japan, [26,41, 42], this study found that a high level of patient involvement in decision-making did not necessarily result in a high level satisfaction for patients.

Considering the findings from this study’s interviews, we assume that the real issue is, as Arora and McHorney [8] and Charles and colleagues [33] states, is how to accommodate to individual preferences in order to maximize the benefits of patient participation rather than merely promoting participation in decision-making per se.. This is a universal demand that is not specific only to Japan. However, we would like to consider the issues identified in the context of the medical system in Japan.

Previous research indicates that there are a number of difficulties associated with judging an individual’s preferences with regards to participation in treatment decision making [43, 44]. In considering how to deal with patient preferences, we argue that the crucial importance is to prepare an appropriate environment in the clinical setting. Doctors need to recognize the importance of promoting a patient-centered atmosphere that can allow patients to take time to consider treatment options and reveal their preferences regarding their desired level of participation. This can be achieved through improved awareness regarding the need for patient participation as well as the use of effective communication skills by health professionals.

While the importance of providing an appropriate atmosphere that allows patients to express their ideas and concerns is recognized, it has been pointed out that one of the
barriers in facilitating shared decision making is patients’ concern about appearing disrespectful to a doctor [45]. Patients hesitate to fully state their desired level of participation, such as in requesting more information or in seeking a second opinion to avoid conflicts with their doctors. In Japan, the strong paternalism that doctors possess toward patients makes it even more difficult for patients to ask for detailed information and records regarding their medical conditions in order to seek a second opinion at other hospitals [42]. It would be necessary both to educate doctors to understand and support patient’s rights in seeking second opinions and to promote communication skills training for doctors. Developing doctors’ skills will hopefully enable them to communicate more effectively with patients in recognizing and counseling patients regarding preferences in treatment decision making.

Secondly, apart from educating doctors, the results of this research point to the need to promote a system to allow patients to obtain a second opinion from other doctors more easily. The first barrier that needs to be addressed is the lack of financial incentive for doctors to provide second opinions which serves as a disincentive for doctors to participate in providing second opinions to patients [42]. Since the national health insurance system in Japan fixes the price of each medical procedure by a uniform fee schedule, doctors are motivated to see as many patients as possible to make profits [46]. Because the consultation fee itself is relatively low, seeing a patient who seeks only a second opinion and who does not require any further testing or examinations is not profitable even if the patient requires a longer consultation time than usual. The more time that doctors take for each patient, the greater the financial loss for the hospital, which makes hospital administrators reluctant to systematically support patients seeking second opinions. To change this situation, it is necessary to
increase the consultation fee in general or set a special consultation fee to provide for second opinions in the fee schedule. Since the Japanese national health insurance system allows people to visit any doctor of their choice, the second opinion system can be facilitated quite easily once the financial barrier is gone. Recently, some hospitals in major cities have opened special clinics that exclusively deal with patients seeking second opinions. In many cases, these clinics finance themselves outside the national health insurance system and set their own prices where patients pay out of pocket for the service resulting in high profitability. The second barrier to obtaining second opinions is that while some doctors will cooperate in lending test results, there is no guarantee that doctors will provide them even though patients have a right to access their chart and test results. Patients hesitate to upset the relationship that they have with their doctors by appearing to be over demanding. Given this situation, seeking a second opinion can mean having to get tests redone, which involves additional cost to the patient. Thus in order to make obtaining a second opinion more accessible for patients and families, a system that guarantees financial reimbursement for the hospitals from the national health insurance system for second opinions and one that allows patients easier access to their test results is needed.

Thirdly, information resources such as leaflets, internet sites, and patient access to libraries in hospitals should be made available in order to promote patients’ understanding of their illness and treatments. A recent study in Japan which surveyed the general public in the Tokyo metropolitan area regarding the sufficiency of medical and health information illustrated the lack of easily accessible, sufficient information about treatments and hospitals for the public [47]. In order to support patients who want make informed decisions, more resources need to be provided to select their
hospitals or treatments. For this purpose, it is strongly desirable to establish more efficient national distribution of educational materials and resources regarding specific diseases and publicize the activities of cancer self-help groups and grassroots non-profit organizations that are trying to cater to the unmet needs of people with cancer [48].

Finally, we would like to acknowledge two major limitations with the current study. One is the recall bias in that interviews with respondents were conducted retrospectively, thus the findings might have been influenced by a number of factors including time elapsing since undergoing treatment and patients’ current health conditions. The other limitation is a skew in the results influenced by the fact that most of the informants who participated in this study were relatively proactive and assertive owing to their membership of a self-help group. Furthermore, all of the informants were not in a terminal stage at the time of diagnosis but had a high chance of survival for certain period of time. We can speculate that if respondents were in advanced states of cancer at the time of diagnosis, it is possible that the communication between their doctors and them may be affected because doctors in Japan often hesitate to disclose full information when the patient has pessimistic prognosis [49]. Further research with participants in a wide range of patient settings would help confirm the participation patterns discussed in this study.

**Conclusions**

We explored Japanese patients’ treatment decision making style and categorized them into 5 types. There are some informants with low level of satisfaction with the
process, despite high level of involvement in treatment decision-making. In order to increase patients’ satisfaction with treatment decision making, we suggest that doctors take a more flexible and individual approach to meet patients’ various levels of preferences in participating in treatment decision making process.

**Competing interests**

The authors declare that they have no competing interest.

**Authors' contributions**

YW was responsible for acquisition, analysis and interpretation of data as well as making contributions to the study conception and design and to the manuscript elaboration. MT participated in the analysis and interpretation of data and made substantial contributions to the manuscript conception and elaboration. IK made substantial contributions to the manuscript conception and elaboration. All authors read and approved the final manuscript.

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References


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Figures

Figure 1 - Types of patients participation in treatment decision-making
# Tables

## Table 1 - Informants' background

<table>
<thead>
<tr>
<th>Informant</th>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Cancer type (primary)</th>
<th>Times since diagnosis</th>
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<td>5 yrs 3 mths</td>
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<td>2 yrs 6 mths</td>
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\(^a\) gastric cancer (17 yrs), colon cancer (7 yrs 6 mths), chondrosarcoma (6 yrs)

\(^b\) colon cancer (14 yrs), lung cancer (7 yrs)