St. Luke’s International University Graduate School of Public Health

Capstone Project

“Impact of doctors’ perceptions of patient-doctor relationship on advance care planning (ACP) in Japan: A mixed methods study.”

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17-MP-109

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10/Feb/2018
Statement about Institutional Review Board approval

This capstone project is approved by St. Luke’s International Hospital Institutional Review Board in Dec 2017.

Abstract

Title: Impact of doctors’ perceptions of patient-doctor relationship on advanced care planning (ACP) in Japan: A mixed methods study.

Background: The patient-doctor trust relationship is typically understood through the lens of good quality of care. The impact of trust relationship with doctor, widely discussed in the literature, suggests that it may potentially work as a facilitator or a barrier. Since there is no consensus of the standard ACP initiation to date, the barriers of ACP implementation into practice are still unclear.

Objective: This study aims to explore the barriers of ACP initiation and promotion from a physician perspective. We hypothesize that a close patient-doctor relationship may hinder doctor’s promotion of ACP.

Design: This is a prospective mixed method exploratory study using qualitative semi-structured interview and a quantitative questionnaire-based pilot survey on Japanese doctors in St. Luke’s International Hospital. The qualitative analysis was conducted using grounded theory. The quantitative analysis used a modified tool to estimate strength of the physician-patient relationship (PPR).

Results: Seventeen doctors were recruited for the pilot phase of this study; the written script for each interview was analyzed qualitatively. Analysis revealed five categories of concepts that may be barriers to ACP implementation: Expectation differences, Individual readiness, Clinical readiness, Education and Ownership. Though the modified PPR tool used in the quantitative pilot survey has not yet been validated in Japan, there appears to be a weak positive correlation between time to ACP and strength of PPR. In comparison, we found no correlation between total number of ACP discussions and strength of PPR.

Conclusion: This study explored the impact of patient-doctor relationship on ACP initiation and the potential barriers of ACP in the Japanese contexts for cancer patients. Overall, the hypothesis was not supported, as stronger patient-doctor trust relationships appear to facilitate the initiation ACP from doctor’s perceptions.
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Background

Definition of advance care planning

Advance care planning (ACP) is a way to think ahead, to describe what’s important to patients, and to ensure other people know patients’ wishes for future care. There are several definitions of ACP worldwide to date, the most recent as follows: “Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.” (Sudore, 2017)

Trends of ACP models: from ‘disease oriented’ into ‘person-centered’ ACP

At present, ACP is recommended as a best practice for all, first in the UK and swiftly becoming accepted internationally. As public values in life have been rapidly changing over the last several decades, ACP has progressively shifted to being more person-centered, enabling self-determination and empowerment of individuals. In short, ACP has a core value of person-centered care in alignment with goals and wishes in broader context of a person’s life. Previous styles of ACP practices mainly focused on discussions requesting permissions for medical treatments and procedures, legally-binding advance decisions to refuse treatment, and nominations for designated spokespersons in case of patient incapacity. It is evolving as a part of standard care, as ACP overlaps with ‘shared decision making’, which is already implemented in health care practices, in terms of the goal of care is to support and enable people through discussions with greater choices at or near the end of life.

Unsuccessful ACP discussions

The literature, both academic and lay, abound with anecdotes of unsuccessful ACP
discussions and practices which should have occurred earlier. Contributing to this delay is the cultural myth that life will go on forever, which makes patients fearful of rushing end of life discussions. ACP also challenges both family and health care professionals to face the reality of care near the end of life.

ACP discussion is sometimes initiated by the person at certain exceptional points in the lifetime, for example, after the experience of a family member’s death. ACP would be also performed by a medical staff during the course of a person’s disease, such as having the prediction of limited lifetime due to the disease progression. However, ACP can be initiated much earlier in life stage and even when the person is healthy, such as at the time of usual health checkups, in the middle of family planning, or when an older adults initiates estate planning, including reflection on personal values and preferences for the future medical care. Because initiation of ACP depends on a host of individual preferences, its timing and form may be especially variable.

**ACP for different chronic diseases**

Furthermore, frequent debates are drawing public attention, that ACP for patients with different types of chronic diseases has been practiced without any consensus. ACP initiation and promotion are considered to be widely variable between many chronic diseases, such as dementia, end stage renal diseases, chronic heart failure, as well as various types of malignancies, such as lung cancer, breast cancer, colon cancer, and prostate cancer. A disease prognosis is an estimation of a limited lifetime, however, even specialists cannot precisely predict prognosis. In addition, cancer treatments have enjoyed a multitude of breakthroughs in the lat several decades, which may make physicians feel almost incapable of choosing what defines the right place and at the right time for performing clinical ACP practices.

**The Guideline of Japanese Ministry of Health, Labor, and Welfare**
Though there is a growing public and professional awareness about ACP, there is broad agreement of a low health literacy in Japan regarding the guideline statements of the Ministry of Health, Labor, and Welfare, “The guideline of decision making process in the end-of-life-care”. To add, the rate of preserving ACP records, including advance directives, is quite low among the general public (3.2%), physicians (5.0%), nurses (3.5%), and nursing care professionals (3.5%) (The Japanese Ministry of Health, Labor, and Welfare, 2016).

It is important to mention that in the Japanese context, there are large disparities from European countries and from the US health care systems due to the limited resources in acute community hospitals and very low rates of utilizing advance directives in hospitals. Public health care facilities have been unable to reach a sufficient level of discussion to date, for example, about the shared outcome measures of effective ACP practices, quality of legal documents correctly reflecting a person’s wishes, and records of ACP discussions with better accessibility when needed. Therefore, as a first step, Japanese researchers need to investigate clinically-based questions concerning what factors are perceived as barriers to ACP practices today for the purpose of better implementation of ACP for the Japanese health care system.

**Literature review**

**Benefits**

A systematic review of older adults about ACP including nine randomized control trials (RCT) demonstrates the potential benefits of ACP for improving the outcome of patient, family and the health care staff with more satisfaction of care and less anxiety of conflicts in decision making, despite a paucity of well-conducted RCTs (Weathers, 2016). Another previous study points out that the benefits of ACP working as a therapeutic practice by improving patient’s quality of life in decision making, patient and family satisfaction, reduced anxiety and depression of surviving family (Detering, 2010). In systematic review, the effectiveness of ACP has been shown to lead to reduction in hospital stays, less intensive care
at the end of life, higher rates of completion of advance directives (AD), increased utilization of hospice care, and to increased likelihood of death in patient’s preferred place (Brinkman-Stoppelenburg, 2014). There is emerging evidence that ACP also reduces financial costs of end of life care without increasing mortality.

**Outcome of ACP**

Since standardized outcomes defining ‘successful’ ACP are lacking, a literature review conducted by five international conferences to identify person-centered ACP outcomes through organizing frameworks and outcome rankings (Sudore, 2018). It claims that without a shared understanding of ACP outcomes, it is difficult to compare clinical results across research and also to determine the most effective ACP programs for the further initiatives of health care systems. Sudore et al. describe the top five outcomes evaluated with Delphi ratings and rankings at the patient-level unit of analysis: 1) care consistent with goals, mean 6.71 (±SD 0.04); 2) surrogate designation, 6.55 (0.45); 3) surrogate documentation, 6.50 (0.11); 4) discussions with surrogates, 6.40 (0.19); and 5) documents and recorded wishes are accessible when needed 6.27 (0.11) (Sudore, 2018).

**Criticisms**

There are debates about the risks of ACP which involves discussions about life and death, which can harm to a person from painful psychological experiences leading to negative emotions. This suggests that there is a risk of ACP overuse, in addition to underused, in the clinical settings. In response to this criticism, there is broad consensus that ACP should be voluntarily performed and patients should not be pushed to having ACP discussions if unwilling. Secondly, changes in preference must be taken into account and reflected in records and legal documents in a timely manner. Thirdly, large gaps between ACP records and actual practice have the potential to lead to legal issues.
Barriers

A systematic review which includes thirteen articles from the UK, Canada, and Australia suggests several categories of barriers in ACP practices. It points out ACP barriers as risk of error, hope denied, promise not honored, and inaction by restrictions of opportunities, such as lack of staffs, time, skills, and resources (Lund, 2015). Another study depicts the complexity of patient-professional interactions. It is still challenging to achieve one form of the best standard of care in ACP, due to variations in individual needs and communication skill, creating a substantial variation of ACP in real medical settings. Another barrier is that doctors seem to be unfamiliar with ACP practices. It is not too much to say that ACP poses inherent barriers, given that ‘parallel planning’ of multiple possibilities in life-limiting condition is quite difficult. There is a dynamic complexity to the initiation of ACP practices for clinicians at the front lines of medical practice.

Patient-physician trust relationship on ACP

The trust relationship has long been understood as critical to the good practice of medical care. However, the literature depicts a potentially negative effect of a poor trust relationship, such as patient preference to discuss future medical plans, including end of life discussions, with an unfamiliar attending physicians during hospitalization (rather than with their own physician). Patients believed these discussions should occur earlier than their physicians do, and that physicians should initiate them. This study revealed three salient perceptions: 28% felt discussions were still not necessary; 26% believed that discussion would not have added benefit; and 22% stated that ACP discussion were an individual-family matter (Dow, 2010). In this context, it is surprising that patients preferred sensitive discussions to happen with a professional without any emotional attachment rather than with their trusted physician, however, the paradoxical effect of patient-doctor relationship has already drawn discussions
into the public before 1990’s, and still seems to exist in some contexts.

**Unsuccessful ACP cases with fair patient-doctor relationships**

In some case of unsuccessful ACP, many clinicians often consider introducing other key players in medical team as a solution. Certain patients may continue to have a high risk of having unsuccessful ACP despite a fair patient-doctor relationship, including patients living alone, those without community social support, those with strong denial of disease progression, and with family who have different opinions leading to an alienation between them. In those circumstances, soliciting contributions from other medical staff, such as nurses, residents, and even palliative care physicians may promote ACP discussions. This is one of the clinical strategies by physicians having experienced difficult situations in unsuccessful ACP discussions and practices. Physicians often perceived that ACP discussion stall, but went smoothly after changing social relationships between the person and the professionals by introducing new members of the discussion team.

**Research project**

**Theme**

ACP is regarded as an intervention to achieve person-centered end of life care reflecting personal preferences and values. The benefits and barriers of ACP from the literature review, and also how to define it and deliver the ACP practices are widely ranged among societies. ACP discussions occur at some key points in a person’s life. Previous literature in the field of family medicine has highlighted that a continuous and longitudinal relationship between doctor and patient may promote better quality of medical care (Ridd, 2011). The trust relationship between patients and physicians is typically understood through the lens of improved patient care. However, given the controversies outlined above, it is possible that this relationship might also exert a negative effect on physicians’ perspectives that prevent
them from initiating ACP for their patients. Various types of barriers remain on the national level that preclude its widespread implementation in practice (Sumita, 2015).

Objective

The objective is to clarify the physician-perceived barriers in clinical practices of ACP promotions. In hospital-based clinical care, there is a lack of collective evidence to draw a conclusion about trust relationship between patients and physicians in hospitals as a positive factor of promoting ACP discussions and practices.

Goals

The goal of the study is to explore whether the patient-doctor trust relationship impacts on ACP as a facilitator or a hindrance for physicians to initiate and promote ACP discussions. In addition, to understand the ‘potential gaps’ between the literature of overseas and the actual ACP practices in Japan, the secondary aim of the study is to understand the factors which hinders ACP practices for cancer patients. Pursuant to this, as the barriers to ACP are not yet fully clarified in the Japanese context, it is essential to first elucidate what barriers exist in current clinical practices in Japan.

Hypothesis

We hypothesize that a close patient-physician relationship may hinder physician promotion of ACP.

Terminology

Definition of ACP

The study anticipates a diverse definition of ACP due to the reflection of physicians’ perceptions as well as the differences in understanding of ACP practices. As it was on
purpose, trying to align with the real clinical practices to seek barriers of unsuccessful ACP of each physician, the interviewer let the physician rephrasing in their own words what is ACP for them without fixing the ACP definition.

**Initiation of ACP**

Though there is no consensus to date of best timing for initiating ACP, perceived late initiation of discussions mostly links to the negative emotions throughout the ACP processes by physicians and other medical staff, which typically understood as an unsuccessful ACP practice in many clinical cases.

**Time to ACP**

The definition of ‘time to ACP’ in this study aligns with the time from first meeting in the hospital, regardless of disease status, to the time of first ACP discussion.

**Unsuccessful ACP**

Unsuccessful ACP practices correlate with physician’s own perception of having a difficulty or making a special effort to initiate the first ACP in vain achieving physician’s dissatisfactions with a need of some improvement throughout the ACP processes when they reconsidered from their own clinical experiences in the interviews.

**Definition of Strength in trust**

The definition of ‘strength in trust’ is generated from Ridd et al. (2011) whose questionnaire-based study posed several questions investigating the strength in trust between patients and their doctors, on both professional and personal levels. Using multiple questions, answers were turned into scale-based scores. Questions included the following: 1.1) Did you see your usual or regular doctor today?; 2.1) I know this doctor very well; 2.2) This doctor
knows me as a person; 2.3) This doctor really knows how I feel about things; 2.4) I know what to expect with this doctor; 2.5) This doctor really cares for me; 2.6) This doctor takes me seriously; 2.7) This doctor accepts me the way I am; 2.8) I feel totally relaxed with this doctor.

Figure 1. Patient-Doctor Depth of Trust Relationship Scales (Ridd, 2011)

**Modified version of the Patient-Doctor Depth of Trust Relationship Scales**

In the quantitative pilot survey, using the Patient-Doctor Depth of Trust Relationship Scales (Ridd, 2011) as a reference, a modified version is used. As the target population of the participants are Japanese physicians, modified scales are changed for the purpose of asking physicians about their perceptions of the patient-doctor relationship. Scales are translated into Japanese in accordance with the general meaning of each original question, with purposeful modification where appropriate. The modified questions for physicians in the study are shown below: 1) I know this patient very well; 2) I know this patient as a person; 3) I really know how this patient feels about things; 4) I know what to expect with this patient; 5) I really care for this patient; 6) I take this patient seriously; 7) I accept this patient the way he/she is; 8) I feel totally relaxed with this patient. This is the first study utilizing those scales in order to describe clinically relevant baseline characteristics of participants and attempt to
quantify the strength of patient-physician relationships.

Figure 2. Modified version of the Patient-Doctor Depth of Trust Relationship Scales

Methods

Target population

Physicians in St. Luke’s International Hospital in Tokyo, Japan.


Exclusion criteria: Physicians trained less than five years as a clinician mainly practicing cancer patient’s treatment and care.

Recruitment of participants

For recruiting the participants, the author’s e-mail invitation of the interview and questionnaire-based pilot survey simultaneously distributed in accordance with the
supervisor’s negotiations to the heads of each department via e-mail; St. Luke’s International Hospital, department of medical oncology, hematology, breast surgery, pulmonology, gastrointestinal internal medicine, palliative care medicine, geriatric health screening, radiology, urology, pediatric surgery, psycho-oncology. This study intended to recruit physicians mainly caring for cancer patients, regardless of ACP experience, including oncologists administering cancer treatments, and physicians practicing cancer screenings and diagnosis. The e-mail invitation included information regarding interview, as well as questionnaire-based pilot survey, and written consent/withdrawal of consent for participation.

**Interview appointment**

After the interviewer received responses from those participants by e-mail accepting study participation, appointments for an approximately thirty-minute interview for each individual participant was made. The place of the interview was in St. Luke’s hospital or St. Luke’s University, mainly in the physician’s own office, meeting rooms, and consultation rooms. Using snowball sampling methodology, further participants were also collected via referral from existing participants.

**Research period**

The research was conducted from December 2017 to January 2018. Data from each recorded interview and questionnaire-based pilot survey was analyzed using a variety of qualitative and quantitative methods in January 2018 as a Capstone project in a Masters of Public Health program.

**Design**

This is a prospective mixed-methods exploratory study of qualitative semi-structured
interview on physicians with a questionnaire-based pilot survey. It focuses on the perspectives of the targeted population, Japanese physicians with a specialty in cancer treatment and care, currently practicing at the front line of an acute private hospital in the center of Tokyo.

**Interview Questions**

The interview consisted of three main questions, with additional questions asked as needed to explore deeper into the barriers and trust patient-physician relationships. Main questions were as follows: Q1) ACP definition, contents of current practices, and educational experiences about ACP; Q2) Unsuccessful ACP experiences, the cause of unsuccessful practices, and the barriers they feel in their own view to initiate and facilitate ACP discussions in these cases; Q3) Patient-physician trust relationship, is it a facilitator or an obstacle for ACP initiation? Examples of unsuccessful cases that they encountered specific difficulties to initiate ACP discussions even with the patient of mutual trust in relationship.

<table>
<thead>
<tr>
<th>The Guidance of the Interview Questions</th>
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<tbody>
<tr>
<td><strong>1)</strong> Questions about your background and ACP practices from your own experience</td>
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<tr>
<td>What is your specialty? How many years after graduations? What kinds of patients are you seeing in clinical hours?</td>
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<tr>
<td>What is your definition of ACP discussions and practices? What kind of clinical practices are you performing as ACP? Please specify in detail.</td>
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<tr>
<td>On what points are you trying to be careful in practicing ACP as a physician? Please specify, on what extent.</td>
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<tr>
<td>How do you think about the essential contents of ACP discussions and practices? Please specify why you think it's necessary.</td>
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<tr>
<td>Have you ever trained about ACP practices? Educations about how to initiate and deliver ACP.</td>
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<tr>
<td><strong>2)</strong> Questions about your experience that you have difficulties in ACP discussions and practices</td>
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<tr>
<td>Question</td>
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<tr>
<td>Have you ever experienced unsuccessful cases of ACP? Please specify when, with whom, in what circumstances. Why do you think it was unsuccessful?</td>
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<tr>
<td>In your past unsuccessful ACP practices, what were the underlying reasons of its unsuccessfulness? Why do you think those are the causes?</td>
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<tr>
<td>Please specify the barriers of ACP initiation and promotion from the physicians side in your opinion, if any.</td>
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<tr>
<td>Please specify the barriers of ACP initiation and promotion from the patient/family side in your opinion, if any.</td>
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<tr>
<td>As a whole, what are the barriers of ACP initiations and promotions in the Japanese context? Please specify if any. Why do you think in that way? Any solution you would like to propose?</td>
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3) Questions about the Patient-Doctor trust relationship in ACP discussions and practices

<table>
<thead>
<tr>
<th>Question</th>
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<tr>
<td>As a clinician, how do you promote good relationship with the patient in your clinical practices? Please specify if any, on what extent.</td>
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<tr>
<td>How do you perceive trust impact on ACP initiation and promotion specifically in your clinical practices? Is it a facilitator, a hindrance, or a neutral factor?</td>
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<tr>
<td>Have you ever noticed you have more difficulty in initiating and promoting ACP with close patient in trust worthy relationships?</td>
</tr>
<tr>
<td>Why did you feel in that way? Is it difficult for you, or much more in general to promote ACP with patient in stronger trust rather than with a person you first met on that day without that level of trust?</td>
</tr>
<tr>
<td>Please notify any barriers and issues of ACP at any levels in your opinion. Any solution for tackling the barriers? How do you wish to change current health care systems in terms of successful ACP?</td>
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**The Questionnaire-based pilot survey**

The pilot survey was consisted with questions taking participants less than fifteen minutes for filling out the survey. The questionnaire consists of three parts; Part A: questions about the physicians’ background, demographics, and training including (age, gender, years of work experience, average numbers of patients); Part B) questions about experience with and knowledge of end of life discussions and ACP; Part C). In part C, physicians are supposed to select one patient that they are actually seeing. Questions include patient demography (age,
gender, cancer type, disease stage at the first meeting), time to ACP (time duration from the first meeting to the first ACP discussion), rate of ACP (total numbers of ACP discussion of selected patient), strength of trust (scored based on the modified version of patient-doctor depth-of-relationship scale). The scales are based on the patient-doctor depth-of-relationship scale is originated from the literature (Ridd, 2011). The quantitative portion mainly consists of multiple choice questions for the descriptive data of the participants. The primary outcome is time to ACP and the secondary outcome is the frequency of ACP discussions with one patient.

The Questionnaire

<table>
<thead>
<tr>
<th>Part A</th>
<th>Q1 Demography of participants (age, gender, year of graduation, year of clinical experiences, specialty)</th>
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<tbody>
<tr>
<td></td>
<td>Q2 Past experiences of cancer treatments and cares (year, frequency of clinical works, average patient numbers)</td>
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| Part B | Q3 Past experiences of palliative cares (year, the Japanese Society of Palliative Care's workshop attendance, average numbers of patients) |
|        | Q4 Past experiences of ACP practices and end-of-life-discussions for inpatients and outpatients (past ACP experiences yes/no, ACP frequency) |
|        | *end-of-life discussions include patient's prognosis, preferences of cares and life sustaining treatments, plans of home care services, living wills, and any preferences in advance of end-of-life cares)|

<p>| Part C | Select Patient A from the past meetings within 1 year (inpatient or outpatient, alive or passed away) |
|        | Q5 Demography of Patient A at the first meeting (age, gender, cancer type, clinical stage, curable/incurable/unpredictable, with/without family) |</p>
<table>
<thead>
<tr>
<th>Q6</th>
<th>When was the first meeting with Patient A (within 1 week/ 1 month/ 2-3 months/ 6 months/ 1 year/ 2 years/ 3-5 years/ 6-10 years/ 10+ years)</th>
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<td></td>
<td>Meeting frequency with Patient A (twice+ a week/ once a week/ twice a month/ once a month/ every 2 months/ twice in 6 months/ twice a year / once a year)</td>
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<td>Q7</td>
<td>Past ACP with Patient A (yes/no, the latest ACP, the first ACP, time to ACP: duration from the first meeting to the first ACP, rate of ACP: total ACP discussions)</td>
</tr>
<tr>
<td>Q8</td>
<td>Select Patient B from the past meetings within 1 year (inpatient or outpatient, alive or passed away)</td>
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<tr>
<td></td>
<td>*if you select Patient A as the one already discussed ACP in the past, please select Patient B as the one have not yet discussed ACP.</td>
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<tr>
<td>Q9</td>
<td>Same question as Q5 about Patient B</td>
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<tr>
<td>Q10</td>
<td>Same question as Q6 about Patient B</td>
</tr>
<tr>
<td>Q11</td>
<td>Same question as Q7 about Patient B</td>
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<tr>
<td>Q12</td>
<td>Same question as Q8 about Patient B</td>
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**Analysis**

Data analysis was conducted by using qualitative method, the Grounded theory, to reveal the main categories of problems that this targeted group of physicians perceive as barriers in ACP practices. By using software NVivo, conversations in interviews were transcribed into written scripts to be analyzed qualitatively. Concepts in similar characteristics were grouped into one category, so that the repetitive phrases referred as barriers in the interview were analyzed as factors extracted from the pool of qualitative data. In the quantitative portion, to examine better patient-physician trust relationship delay the initiation of ACP discussions (time to ACP as a primary outcome) and resulted less frequent ACP discussions (frequency of ACP as a secondary outcome) with the patient, R software was used to validate the correlation between those factors.

**Grounded Theory**

Grounded Theory is one of the dominant methods of qualitative studies. In the study, as
utilizing Grounded Theory by categorizing phrases in the interview into more general conceptual groups. This process is called ‘Coding’ in the qualitative analysis. The purpose of coding is to look into the underlying key factors from the original sources. Firstly, translating interviews into transcripts. Then look into the scripts to raise potential themes from the phrases in the interview scripts as ‘open coding’ which is initially labelling analytical categories of concepts. Adding more data source from the interview scripts as the researcher seeing the categorical themes emerging throughout the interviews, comparing more general categories repeatedly appeared in each participant. Some themes in common are similar among the several interviews from different persons, then compare these categories with similarities. Making links between categories from the data, trying not to be biased by the interviewer’s perceptions, and connecting ideas with theoretical links or combine, making subcategories if any.

In this manner, the theoretical model would be driven through critical thinking processes. Lastly, checking the models against the data, trying not to overreach the conclusion, the researcher present the analysis based on the quotes which illustrates the theory, which is getting grounded by each analysis added from the qualitative data (Bernard, 2017).

<table>
<thead>
<tr>
<th>Grounded Theory process (Bernard, 2017)</th>
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<tbody>
<tr>
<td>1. Produce transcripts of interviews and read through a small sample of text</td>
</tr>
<tr>
<td>2. Identify potential analytic categories (which are potential themes) that arise</td>
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<tr>
<td>3. As the categories emerge, pull together all the data from those categories and compare them</td>
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<tr>
<td>4. Consider how categories are linked together</td>
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<tr>
<td>5. Use the relations among categories to build theoretical models, constantly checking the models against data, especially against negative cases</td>
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<tr>
<td>6. Present the results of the analysis using quotes from the interviews that illuminate the theory</td>
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</table>

Example of analytical process
For example, a phrase from the interview in the study is that, “In my opinion, systematic assessment skills should be obtained by the physicians through trainings.” This phrase turned into a category of ‘education’. The name of the categories illustrate the clear concept that is not overlapping the other categories. If it overlaps to the other categories, the researcher carefully go back the analytical processes to draw more precise conceptual themes and rename the categories by sorting qualitative data in more proper way. Links between the conceptual groups by explaining relationships between themes depending of their levels of ‘importance’ in the analytical process is essential to draw a conclusion of the qualitative study. Grounded theory process is often compared to ‘a spiral’, which starts from collecting data slices into continuous process of conceptualizing the themes codified, moving toward to raise the theory onto the ground. Theorizing is involved in all these steps as it is required to build and test theory all the way through until the end of a project (Bernard, 2017).

<table>
<thead>
<tr>
<th>Terminology in Grounded Theory (Bernard, 2017)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Codes</strong></td>
</tr>
<tr>
<td><strong>Concepts</strong></td>
</tr>
<tr>
<td><strong>Categories</strong></td>
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<tr>
<td><strong>Theory</strong></td>
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**Results**

**Descriptive analysis**

The seventeen participants were recruited for the interview. Participant’s demography, gender and age distribution, clinical experiences and specialty are explained in Table1. Four out of seventeen participants were females (24%) and thirteen were males (76%). Six out of seventeen were in their thirties (37%), four were in their forties (25%), another four were in fifties (25%), and two were in sixties and above (13%). Clinical experiences varied from six years of post-graduated years (PGY) to more than fifty years of clinical experiences.
Participant’s specialty were as follows, five out of seventeen were medical oncologists (29%), three were palliative care physicians (17%), two hematologists (12%), two pulmonologists (12%), two breast surgeons (12%), and the others were one urologist (6%), one pediatric surgeon (6%), and one geriatrician (6%).

<table>
<thead>
<tr>
<th>No</th>
<th>Gender</th>
<th>Age group</th>
<th>Clinical experience (PGY)</th>
<th>Specialty</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>30</td>
<td>12</td>
<td>Breast surgeon</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>50</td>
<td>30</td>
<td>Medical oncologist</td>
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Table 1: Demography of participants

Five categories of concepts as ACP barriers revealed by coding

The study revealed that there are five categories of ‘barriers’ in ACP practices from physicians’ perspectives. Factors were categorized into the similar conceptual groups by ‘coding’ in Grounded Theory, grouping the repetitive concepts appeared in the interviews to reveal the underlying general themes. The concepts were categorized into those groups counted as follows; 1. Expectation differences (107) / 2. Individual readiness (53) / 3. Clinical readiness (35) / 4. Education (54) / 5. Ownership (56) / other barriers (18)
Figure 1: Five categories of concepts as ACP barriers by coding

Descriptions of categories

Expectation differences

The description of each concept will be explained in detail. Firstly, the Expectation differences were the most frequently appeared concept in the interview. There were the expectation differences among people who had different point of view, including the differences of expectations from patient’s side, families’ side, physicians’ side, and other health care professionals’ side. Also it involves expectation differences between physicians in different positions, between generations and cultures in the public, between definitions of ACP practices by individuals. In the meantime, not only differences among persons, but also differences among the expectations of disease recognitions, predictions of prognosis, treatment preferences, personal values, professional responsibilities, and perceptions of health
care provider’s role, and so on.

“The largest gap is knowledge. I cannot deny that there is a large gap between the recognition of current disease status by the patient, family and the hospital staffs.”

“Even with the standard level of medical care, your disease won’t be cured and your lifetime is limited, to be realistic not more than three months. But, if I won’t tell honestly and sincerely, patients tend to misunderstand the reality, don’t they?”

“Of course there are times that ‘the good practice’ for patient because they have their own values, which is not overlapping what I believe ‘this is my good practice’ for them”

**Individual readiness**

Individual readiness covers lack of readiness by the patient, family, physician, and other health care workers. Secondary, individual readiness were divided into those subcategories that the denial of death, the psychological and emotional refusal of disease progression, lack of medical information about current situation, lack of consciousness about aging nearing to death, and the cultural incapability in Japanese context regarding a topic related to death as a taboo.

“In some stages of denial, having a conversation about death often makes the patient’s overreaction of refusal rather than admitting it”

“I can see that there are some patients really understood and well-prepared for it even though they won’t actually say it out loud ‘I understand the situation’ by words”

“The patients in their seventy or above, maybe it is a cultural perception that the life expectancy will get longer and longer in these days, but those people are having very difficult time to accept death in their lifetime. They seem to believe they can get over it forever”

**Clinical readiness**

In contrast, clinical readiness is defined as a group of concepts mainly drew from an
unforeseen disease status. Lack of clinical readiness appeared in several phrases explaining the unsuccessful ACP discussions with an unforeseen rapid disease progression, an uncertain clinical course of the disease, and even in some stable status of the disease. Moreover, clinical readiness depicts lack of resources in hospitals to catch up the patient preferences at the time of crisis, and lack of discussion between patient and professionals before the disease gets really severe.

“It seems very stable at first, but suddenly the disease got progressive and it was so rapid. On top of that, the family living in a remote area had a very tight schedule so couldn’t be on time to obtain enough social resources for the patient”

“I really understand the difficulty for the doctors to initiate the discussions in loneliness and without any help of other staffs, in this unforeseen situation, and in the bad timing of patient’s deep sorrow”

“Under the circumstances of having a severe chronic disease, these conversations are much more a heavy burden for the patient. If we could carry out ACP discussion earlier, in advance of those events, it might work much better and easier for them, I guess”

**Education**

The fourth category, education, is set as an another group for it refers lack of knowledge, experiences, skills, communications, and understanding of ACP as a good clinical care in global context by the public, patient, family, physicians and by other health care professionals.

“In my opinion, systematic assessment skills should be obtained by the physicians in learning through trainings”

“That’s it, absolutely. That’s correct. It really a great opportunity for patient at least to talk about it. We should have chances for making time for thinking about it”

“I hope we will have more open atmosphere to casually talk about it in public”
Ownership

The fifth category of ‘barriers in ACP practices’ was lack of ownership as well as various level of ownership making confusions among the key players in decision making process of ACP practices in Japan. Unsuccessful ACP discussions were drawn from lack of common ownership, collective ownership, public ownership, divided ownership, co-ownership or joint ownership, and a system of ownership of ACP, which seems an emerging issue to be tackled for the better practices of ACP in various clinical settings. This category includes too little and too much responsibility of moving the ACP discussions forward, not in accordance with the person’s preferences or without the consensus of team members promising the high quality person-centered cares.

“Lately, it is quite rare that one physician will be in responsible for all the treatment and care for the patient as the prognosis of many cancers are improving and the treatment options are increasing. So often physicians relay for the patient passing the information to the next player”

“Some patient seem to be given all the important decisions in responsible up to their physicians”

“No wonder an individual professional cannot manage everything. So coordinating team-based care is the key for those cancer patients”

Others

Other barriers mentioned by the physicians were lack of the standard record system of ACP discussions, lack of supports for ethical and legal issues in the hospital, especially in case of having troubles and conflicts among family members.

“If the patient’s family, for example the wife of the patient told me ‘please don’t tell this to my husband’, in that situation rather than hiding the truth, instead I’ll tell her that ‘your
husband is saying he would like to know’ by letting know the family the patient’s own preferences of care. That’s fundamental because it begins when the person comes to me, we’re acting because of the patient’s need, which should not be forgotten”

“How to reflect the inconsistent preferences of the patient actively and correctly in records might be the most difficult part in our systems”

“Somebody should say that it’s terrible that other professionals are pushing physicians to do this practice without an exception. We all know its importance but there are exceptions for it is improper”

**Impact of Patient-Doctor Trust Relationship**

**From the Interview**

In the interview, fourteen out of seventeen physicians referred patient-physician trust does impact greatly on initiating ACP discussion, eight answered it is a facilitator while three stated it is neutral, and six believed it is a hindrance on ACP initiation.

“When the conversation of the preferences of end-of-life care pops up, it’s because there must be a casual trust relationship, or the patient won’t disclose, I suppose” —a facilitator

“The conversation itself is quite hard for everybody to initiate. Even though there is a tight relationship already built, it not that easy for both of the patient and the physician to make it happen” —a neutral

“With a person I met for the first time, because of that, I would rather be careful and deliberately discuss in good manners. In contrast, with a person known each other for a long time, I might skip some processes in the conversations. It might be a bias of me, but death of the patient I know well makes me feel like avoiding the serious conversation sometimes” —a hindrance

**From the Questionnaire-based pilot survey**
As shown in Table 2, from the questionnaire-based pilot study, data was collected from ten out of seventeen participants. The mean scores of ‘the time to ACP’ was 8 weeks (range: 0.5-24), the mean frequency of ‘total ACP discussions’ was 4.2 (range: 1-12), and the mean score of ‘the strength in trust’ was 21.6 points (range: 10-28, full score: 32).

In Figure 2, there seemed to be a weak positive correlation between ‘the time to ACP’ and ‘the strength in trust’, which implies that more trust relationship in physician’s own perception hinder an initiation of ACP, resulting in a delay of the first ACP discussion for cancer patients. In comparison, in Figure 3, no correlation between ‘total number of ACP’ and ‘the strength in trust’. As it is mentioned, the quantitative pilot survey is for exploring the potential participants’ background. The results did not support the hypothesis. Furthermore, the scoring methods is not validated.

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Table2: Time to ACP, Total ACP and Strength in Trust
Figure 2. Time to ACP and Strength in Trust

Figure 3. Total numbers of ACP and Strength in Trust
Discussions

Impact of Patient-Doctor Trust Relationship

As not yet revealed in the Japanese context, this is the first study aims to understand the impact of patient-doctor relationship on ACP initiations and promotions. In this study, few participant mentioned that the patient-doctor trust relationship works as a barrier, especially in advance of the interviewer's focused questions about the clinical impact of trust in ACP promotions. In comparison, a few pointed out that a trust relationship often triggers patients to carry out ACP discussions by themselves to their doctors, since it is a fundamental requirement for health care professionals to smoothly open up discussions by making a comfortable atmosphere for the patient. The art of ACP practices is by gradually making the trust relationship between the person and the doctor for promoting ACP in a successful way.

The hypothesis was not supported by the study results and the analysis from the reasons explained above. Furthermore, it is quite worthwhile to note that the trust relationship seems to have a great dynamics in the practices of ACP in the Japanese context. if asked by the interviewer whether the patient-doctor trust relationships hinder the initiations and promotions of ACP or not, the answers totally varied.

Facilitators of ACP discussions

One third of the participants claimed patient-doctor trust relationship is a facilitator in ACP for it is a fundamental basis for patients to let their doctors know own personal values in spite of its difficulties by nature to carried out in any circumstances. Patient-doctor trust relationship enables ACP discussions to have more opportunities to reflect personal preferences and future wishes than those relationships without it. It is persuasive in the qualitative analysis that a patient-doctor relationship itself facilitates ACP discussions rather than hinders ACP initiations. It supported the literatures that fair longitudinal relationships with trust considered to encourage doctors to initiate those sensitive discussions putting into
practices, which is also observed in the Japanese context.

**Barriers in ACP practices in Japan**

Barriers of ACP in an acute hospital from doctor's perspective in this study are categorized into five different themes as *Expectation differences, Individual readiness, Clinical readiness, Education, and Ownership*. The results are supported by the literature of a qualitative descriptive study aiming at exploring ACP barriers and facilitators, which revealed three categories: 1) person (beliefs, attitudes, experiences, health status); 2) access (to doctors and health care providers, information, tools and infrastructures to communicate ACP preferences); and 3) the interaction with the doctor (who and how initiated, location, timing, quality of communication, relationship with doctor). (Simon, 2013) Since cultural differences impact on behaviors to a large extent, barriers in ACP might vary between cultures.

The literature from Canada shares several basic components of ACP barriers in Japan, especially in the interactions with doctors in terms of arguing what really matters in ACP practices is “Who initiate it, location and timing, relationships with the doctor and quality and ease of comprehension of communication.” (Simon, 2013) To establish a comfortable atmosphere to make ACP naturally pops up in ordinary conversations with less discomforts is the key for a successful ACP practices for both of the patient and the doctor. The literature emphasizes that “Relationship with doctor is central to feeling supported in the conversation” (Simon, 2013) so that ensuring doctor’s educations including communication skills is quite important. Similarly, it is expected to have positive behavioral changes in doctors’ communication skills through education for it is an essential way to improve the quality of care in ACP practices by the Japanese doctors.

**When does patient-doctor trust relationship become a barrier in ACP?**

In some context, doctors perceive trust relationship does hinder ACP promotions, which
is discussed with these phrases in the interview.

“In the initiation of ACP, physician tend to feel psychological difficulty due to the risk of breaking the patient-doctor relationships into pieces by opening up a critical ACP discussion.”

One third of the participants agreed that trust hinders ACP discussions due to the fairness of continuous relationship they wish to have as long as they could in some stable diseases. ACP discussions have potentials of breaking the fair trust relationships already built between the patient and the doctor, so that this group of doctors admitted that they cannot deny there's a negative emotion toward a patient in fair trust relationships to break the stability by themselves by carrying out critical ACP discussions for them.

**Neither agree nor disagree ACP as a hindrance**

Another one third of participants doubt that the trust relationships is either a facilitator or a hindrance, because the opportunities of having ACP discussions are equally given no matter how close the relationship is. Participants in this group also mentioned that doctors have responsibility of letting those discussions happen between patients even without a trust, because of the sincere sense of mission perceived by the doctors caring cancer patients. In some emergent situations, doctors have to make it happen, even they have just met or having troubles communicating with, participants with a neutral opinion raised those points.

**Variation in the definition of ACP practices**

There is a variation of the definition of current ACP practices among the Japanese doctors, which causes a confusion in implementing ACP into current clinical practices. Providing a chance to stop, think, and consider ‘What are the priorities in life’ is important for the person is that most of the doctors mentioned in the interview. In most of the Japanese community hospitals, there is no standard form of ACP at the current phase, but some emerging programs
of ACP practices on a team-based approach seem to lead a paradigm shift in the near future to see ACP practices implemented into the standard of care. Some participants pointed out that they have already implemented narrative ACP practices into the standard as the person-centered care for cancer patients. They deliberately discuss at the very early stage of disease or even before the disease happen, asking preferences of life and death. This group of doctors really care for the timing of initiating ACP, especially at some critical turning points in the disease course, they struggle to deliver the information about ACP and further discussion opportunities up to the person with their own ownership.

**Exploring solutions for barriers in ACP in Japan**

**Team-based approach for person-centered ACP**

The critical differences between recognitions often lead to miscommunications between patient and the doctor, which results mostly in unsuccessful ACP practices, especially in an emergency. However, to fill up the gaps, such as knowledge, accessibility to health information, awareness of current disease status, as well as the levels of strength in responsibilities among the key players in ACP practices in hospitals. It is a lesson for all to make sure how much they share the goal of ACP correctly in accordance with the patient’s personal values and needs for future cares. It takes time in clinical setting with limited resources, thus with the coordination of team-based care with person-centered medicine, these *Expectation differences* between key players in ACP discussions that might lead to poor outcomes of ACP will turn out to be better.

**Culture of Physician-dependent relationship**

*Ownership* of fulfilling professional roles of health care practitioners is important for promoting the shared decision making in team-based cares. Too much responsibility needs adjustment and too little awareness needs to be empowered to have many successes with the
positive consequences. The equity of distribution of the force to pushing a sailing ship to forward and keeping the balance to not to lose control is ‘the art’ of the ACP practices.

**Infrastructure and actions to develop ACP systems**

In St. Luke’s International Hospital, there is an official document called ‘my living will’ records from nine years ago and also there has been a ACP team in hospital, but not widely recognized and working effectively. A systematic actions for ACP to be implemented as standard of care without overused and underused is in process. It is notable that quite a few doctors feel the necessity of ACP discussions to happen in more open space by the public, in which everybody can casually speak out their own goals of life and future preferences of cares.

**Future discussions of ACP**

A trust relationship between the patient and doctor perceived through the lens of Japanese doctors was understood as a facilitator of person-centered goal of care in ACP practices. The relationship with the doctor potentially have the primary impact on patients to share their personal values in life and preferences of future cares. To make it happen appropriately in the public discussions, understanding the impacts of doctors’ communications on patients is necessary. Therefore, to achieve the patient’s goals of cares, not just implementing ACP practices into the Japanese health care system, empowering the public with the population-based approach through the public health education is essential.

**Issues to be tackled in ACP**

Improving doctor’s understandings of ACP benefits and harms by promoting more open discussions about ACP as well as establishing collective evidence from the public health researchers is the key for promoting cultural oriented ACP practices in each context. For
more person-centered ACP practices, understanding who, when, how to initiate ACP are the fundamental questions need to research further in ACP practices, and how to achieve standardized ACP outcomes in accordance with the person’s wishes are the issues to be tackled.

**Conclusion**

In conclusion, the hypothesis that stronger patient-doctor trust relationships hinder ACP initiations and promotions was not supported by the study results. As it is perceived as a good quality of care, trust in patient-physician relationship facilitates ACP discussions to take place. However, this mix-methods study explored there is a diverse perceptions of doctors when to initiate ACP discussions in an acute community hospital practices as there is no consensus up to now. It is suggested that there are several groups of concepts typically understood as barriers for Japanese doctors to initiate ACP for cancer patients: Expectation differences; Individual readiness; Clinical readiness; Education and Ownership. The value of this study is that it is the first study which explored barriers of ACP and the impact of relationships with doctors on ACP initiation and promotion for Japanese cancer patients.

**Limitations**

The complexity of relationships and their biases from the interviewer’s side and participant’s side cannot be diminished. In addition, recall biases in the interviews by the participants exist in this study.

The modified patient-doctor depth of trust relationship scales in the analysis were not yet validated. Possibility of the interviewer’s bias in the qualitative analysis with Grounded Theory.
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doi:10.1093/oso/9780198802136.001.0001


doi: 10.1371/journal.pone.0116629


