





Improving person-centered advance care planning conversation with older people: a qualitative study of core components perceived by healthcare professionals

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Abstract

Objective: The non-medical needs of patients, such as values and personal preferences, are likely to be omitted from advance care planning (ACP) discussions because of a lack of readiness and awareness on the part of healthcare professionals. The aim of the present study was to identify core components perceived by multidisciplinary healthcare professionals to improve person-centered ACP conversations with older people.

Methods: The study participants were healthcare professionals (physicians, nurses, and care managers) working in different cities. This qualitative study was performed online using eight individual in-depth interviews and one subsequent focus group composed of eight healthcare professionals. The interviews and focus group discussion were audio-recorded online and transcribed verbatim. The aim of the analysis of the individual in-depth interviews was to summarize the transcribed results, create a conceptual framework for person-centered ACP conversation, and provide meaningful interpretations of the focus group participant discourse. The qualitative data were then analyzed by inductive manual coding using a qualitative content analysis approach.

Results: Five themes capturing the core components for successful person-centered ACP were extracted from the ideas voiced by participants: Placing highest value on patient autonomy and human life; uncovering patient's true feelings and desires; sharing collected information on patients' end-of-life wishes with other team members; relaying patients' wishes to the physician; and handling conflicts among patients, relatives, and healthcare professionals.

Conclusion: The results provide guidelines for the future development of novel, value-based, person-centered ACP practice for multidisciplinary healthcare professionals.

Key words: person-centered care, advance care planning, practice guideline, paternalism, multidisciplinary collaboration

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Introduction

Advance care planning (ACP) is a process that allows people to receive guidance and make plans about the type

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of healthcare they would like to receive at the end of their life should they become unable to communicate their preferences or make decisions¹⁾. For patients, the goal of ACP is to articulate their personal values, life goals, and preferences regarding future medical care¹⁾. Previous studies revealed that successful ACP was beneficial for patients, relatives, and healthcare professionals because it promotes greater patient autonomy, fosters dignity, and results in greater satisfaction for families and healthcare professionals through improved concordance between preferences for care and delivered care²⁾.

Previous studies and literature emphasized that although ACP should focus on the psychosocial aspects of patients' end-of-life wishes, hospital and primary physicians lack the time, training, experience, and confidence to delve into

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these issues with patients³⁻⁶). Numerous studies have suggested that the opportunity for ACP discussion needs to be provided at the right time in a multidisciplinary, collaborative manner⁷⁻¹⁰⁾. In Japanese community-based integrated care settings, home-visiting nurses, care managers, and social workers with ACP training could be in a better position to understand the common barriers to ACP and address patients' psychosocial concerns than physicians whose time is often restricted¹¹⁾. Under the Japanese long-term care insurance system, aspiring care managers need to acquire the Care Manager Certification, which prepares them to assess their clients' needs, create care plans, and monitor their patients' condition from the early stages of frailty¹²⁾. Thus, Japanese care managers are educated and experienced geriatric social workers who are expected to provide mental, emotional, and social support to their older clients while also connecting them to resources in the community according to their individual needs.

When carried out comprehensively, ACP involves talking about psychosocial matters such as patients' values and preferences with patients, families and healthcare providers, and documenting them in an advance directive, which usually consists of the designation of a healthcare proxy or durable power of attorney, refusal of unwanted invasive treatments, preferred priority of care, and preferred place of care¹³⁾. However, previous studies have noted that patients' non-medical needs such as values and personal preferences were likely to be omitted from ACP discussions because of a lack of readiness and awareness on the part of healthcare professionals^{14–16}). There is a recognized need for the provision of training and support for healthcare professionals including physicians, nurses, and care managers to acquire the skills needed to lead value-based ACP discussions from a person-centered perspective.

A systematic review and meta-analysis by Oczkowski et al.¹⁷⁾ suggested that the use of structured communication tools might encourage the communication of preferred care. Another systematic review by Cardona-Morrell et al.¹⁸⁾ concluded that available decision aids seemed to enhance patients and surrogates' knowledge of possible care options. However, the studies included in these systematic reviews did not specifically focus on ACP conversation guides for healthcare professionals. Thus, the present study was conducted to identify core components to guide the development of a novel value-based, person-centered ACP practice guideline for multidisciplinary healthcare professionals.

Methods

Design of the study

This qualitative study was performed online using eight individual in-depth interviews and one subsequent focus group composed of eight healthcare professionals. Members of the research team were all qualitative research experts with more than eight years of experience in the field.

Participants

The study participants were healthcare professionals (physicians, nurses, and care managers) working in different cities (Table 1). Participants for the individual indepth interviews were recruited via a convenient sampling method¹⁹. Researchers adopt this method to collect research data from a conveniently available pool of potential eligible participants. All potential eligible participants from the individual in-depth interviews were experienced nurses and care managers with more than ten years of experience in ACP practices. The research team recruited participants for the focus group. An e-mail was sent to the research team-led online nationwide platform for multidisciplinary case study discussion, informing of the objectives and specifics of the focus group, and asking for collaboration. Eight members of the platform agreed to take part in the focus group.

Data collection

An individual in-depth interview is a one-on-one interview that aims to collect detailed information beyond initial surface-level responses. The focus group method is used to measure the reaction of participants to a new product and usually provides immediate ideas to improve particular products or concepts²⁰⁾. In this study, a focus group was used to triangulate the findings extracted from preceding individual in-depth interviews. Here, all focus group participants discussed the findings to add new ideas. Altogether, the individual interviews and focus group lasted an average of 60 min, and were conducted by 2 members of the research team with experience as workshop moderators. Both the individual interviews and focus group addressed the following topics concerning person-centered ACP, which had previously been developed by the research team: points of concern regarding ACP interviews, communication with relatives and healthcare professionals, and obstacles to improving healthcare professionals' ACP attitudes and skills. These topics were discussed in a flexible way and opinions could be modified during the course of the interviews to capture novel ideas. All of the individual interview and focus group participants were acquainted with the members of the research team, so they were at ease to express their ideas and opinions.

Analysis

The interviews and focus group discussion were audiorecorded online and transcribed verbatim. The aim of the analysis of the individual in-depth interviews was to summarize the transcribed results, create a conceptual framework for person-centered ACP conversation, and provide meaningful interpretations of the focus group participant

Table 1 Characteristics of participants

Code	Profession	City	Gender	Age range	Other relavant information
Depth interview 1	Nurse	Urban Nagoya	Female	55-60	Head nurse with over twenty years of experience in practice of institutional care
Depth interview 2	Nurse	Urban Himeji	Female	55-60	Head nurse with over thirty years of experience in practice of home-visit care
Depth interview 3	Nurse	Rural Tokushima	Female	45–50	Public health nurse with over fifteen years of experience in practice of home-visit care
Depth interview 4	Care manager	Urban Akita	Female	40-45	Care manager with over fifteen years of experience in practice of home-visit care
Depth interview 5	Care manager	Urban Nagoya	Female	55-60	Care manager with over twenty years of experience in practice of home-visit care
Depth interview 6	Care manager	Urban Nagoya	Male	50-55	Care maanger with over twenty years of experience in practice of institutional care
Depth interview 7	Care manager	Rural Nagoya	Female	50-55	Head care manager with over twenty years of experience in practice of home-visit care
Depth interview 8	Care manager	Rural Nagoya	Female	45–50	Head care manager with over twenty years of experience in practice of home-visit care
Focus group 1	Physician	Urban Akita	Male	55–60	University faculty member with over twenty years of experience in practice of primary palliative care
Focus group 2	Physician	Urban Akita	Male	55-60	Home-visit physician with twenty years of experience
Focus group 3	Physician	Urban Akita	Male	50-55	Home-visit physician with over twenty years of experience
Focus group 4	Physician	Rural Akita	Male	50-55	Primary care physician with over twenty years of experience in practice of both hospital and home-visit care
Focus group 5	Physician	Rural Tokyo	Male	25-30	Hospital physician with five years of clinical experience
Focus group 6	Nurse	Urban Akita	Female	30-35	Home-visit nurse with over ten years of clinical experience
Focus group 7	Care manager	Urban Akita	Female	40-45	Care manager with fifteen years of experience in practice of home-visit care
Focus group 8	Pharmacist	Urban Akita	Male	45-50	Community phamacist with twenty years of clinical experience

discourse. This framework was used to identify categories and interpret the data from the focus group. The first author read the transcriptions repeatedly to become acquainted with the data, and performed data cleansing to ensure clarity and enhance readability: meaning was refined where needed by adding additional words in parentheses, converting fragments into full sentences, and fully spelling out abbreviations and acronyms. The qualitative data were then analyzed by inductive manual coding using a qualitative content analysis approach²¹⁾. First, the first and second authors performed line-by-line labeling, where pieces of data were segmented and condensed into individual sentences. Then, the emergent labels were organized through group discussions among all research members. The grouping process involved reading and comparing individual labels to cluster similar ones into categories and inductively formulate themes. The research team members thoroughly discussed the identified codes and categories until full consensus was reached. The analysis was manually conducted, and not supported by any commercially available software.

Ethical considerations

This study was reviewed and approved by the Bioethics Review Committee of Nagoya University Graduate School of Medicine. All participants were informed of the objectives of the study, and were notified of their right to withdraw from the study at any time and to skip questions or topics they did not wish to discuss.

Results

Five themes capturing the core components for successful person-centered ACP conversation were extracted from the ideas voiced by the participants: Placing highest value on patient autonomy and human life; uncovering patients' true feelings and desires; sharing collected information on patients' end-of-life wishes with other team members; relaying patients' wishes to the physician; and handling conflicts among patient, relatives, and healthcare professionals. No other themes were identified from the focus group.

Placing highest value on patient autonomy and human life

ACP plays a key role in promoting patient autonomy and improving quality of life through the fulfillment of personal desires at the end of life. Patient autonomy, a critical determinant of quality of life, is a fundamental principle of professional medical ethics. The ability to recognize and foster patient autonomy in all its dimensions is widely recognized as an important clinical competency for healthcare professionals. Too often, however, according to participants, it is compromised either because of neglect or the paternalistic mentality pervasive among healthcare professionals.

"I realized that I tended to stigmatize people with dementia or other disabilities and was unable to listen to them without judging their decision making ability". (Indepth interview 6)

"Many healthcare professionals do not let older people with cognitive impairment choose to dress themselves and have them wear comfortable clothing to facilitate their work". (In-depth interview 3)

"When clients are transferred from one institution to another, only basic patient information such as diagnosis and physical assessment is forwarded, without any mention of their values and preferences". (In-depth interview 1)

Uncovering patients' true feelings and desires

New patients are particularly vulnerable because without rapport with their healthcare providers, they tend to shy away from expressing their real emotions. They might also drop out of person-centered care completely. While ACP discussions help patients voice their end-of-life needs, rapport building among the patient, relatives, and healthcare professionals is necessary to collect more specific and honest information. Time constraints also prevent physicians and nurses from initiating and deepening ACP discussions with their patients. In addition, some participants noticed that a number of older patients have difficulty speaking frankly about their wishes in front of their relatives.

"Many healthcare professionals discuss ACP rather superficially and make impersonal care plans without confirming their patients' opinions". (In-depth interview 3) "Not wanting to bother their children, many older people choose to be institutionalized even though they would truly prefer to spend the last years of their life at home". (In-depth interview 5)

"If I notice that my clients are reluctant to voice their preferences in front of their relatives, I visit them when family members are absent". (In-depth interview 8)

Sharing collected information on patients' endof-life wishes with other team members

One fundamental barrier to successful ACP is healthcare

professionals' lack of time for discussions with patients. To overcome this, individual team members should collect information on their patients' end-of-life wishes to be shared collectively. For example, each team member could take daily notes of the information gathered through brief conversations with individual clients and share these with other team members, and deductions could thus jointly be made regarding a patient's end-of-life wishes. However, a number of participants indicated a lack of opportunities to share information with healthcare teams, which negatively affected person-centered care.

"Caring staff understand their clients' values and preferences better than care managers because they meet their clients more often". (In-depth interview 7)

"Even when staff listen to their clients' life history and document their findings in care records, multi-professional conference members often ignore them for lack of time". (In-depth interview 1)

Relaying patients' wishes to physicians

Ideally, physicians should be sensitive to each patient's individual circumstances and preferences when engaging in ACP discussions. If physicians approach ACP from the perspective of their patients' quality of life, patients may feel reassured and encouraged to express their true feelings. However, in reality, partly owing to a lack of time, physicians focus only on the living will and proxy decision making, and generally ignore their patients' values and preferences. Participants reported that to counter this, they try to advocate for their clients.

"Even if it goes against their wishes, many older people agree to be institutionalized if their physician suggests they should not be living alone". (In-depth interview 4) "I think home visiting nurses are the right persons to facilitate communication between physicians and care managers. Many care managers don't feel concerned about ACP because they view it as a medical issue. As a pharmacist, I want to serve as an intermediary to facilitate communication between physicians and care managers". (Focus group 8)

Handling conflicts among patients, relatives, and healthcare professionals

Healthcare professionals often encounter ethical dilemmas surrounding autonomy and consent, truth-telling, confidentiality, preservation of life, and justice in their clinical practice, especially with regard to palliative and end-of-life care. Therefore, patients, families, and healthcare professionals are likely to experience a significant degree of decisional conflict about the best course of end-of-life care. Some care managers felt a sense of responsibility for conflict management and mitigation through ACP.

"In the case of older patients who have difficulty swal-

lowing, without ACP, their family and healthcare professionals had conflicting opinions about the use of tube feeding in their care: caring staff and relatives want them to continue to eat, while physicians do not (family/caring staff vs. the physician)". (In-depth interview 3) "I cared for an older patient with advanced dementia who wished to live in a group home until the end-of-life. However, I had no other choice but to transfer him to the emergency room against his will because of the unexpected occurrence of hematemesis". (Focus group 4) "I have witnessed on several occasions an older couple living together being forcibly institutionalized by their children for safety reasons". (In-depth interview 7)

Discussion

This study provided new information about clinical practice guideline topics for improving person-centered ACP: placing highest value on patient autonomy and human life; uncovering patients' true feelings and desires; sharing collected information on patients' end-of-life wishes with other team members; relaying patients' wishes to physicians; and handling conflicts among patients, relatives, and healthcare professionals.

The results suggested that healthcare professionals recognized the importance of patient autonomy. A better understanding of autonomy could facilitate the ultimate goal of implementing a patient-centered approach and ensure compassionate, high-quality care that respects patients' values²²⁾. Historically, medical decision making has been rooted in paternalism, with the physician cast as the wise healer and the patient as the passive recipient of care²³⁾. In Japan and other Asian countries, patients' expectations and the role of the doctor in the patient-physician relationship are changing, and the idea that individual patients should have the freedom to make choices about their lives, including on medical matters, has become gradually prominent in the current literature²⁴⁻²⁹⁾. Thus, the question of "who decides" has shifted from paternalism (physician-driven decision making) to autonomy (patient or surrogate-driven decision making)²⁴⁾. However, the move toward greater patient autonomy in medical decision making has been slow in palliative care settings where paternalistic attitudes continue to prevail, partly because of the burden of making decisions in stressful life-threatening situations. In these situations, some patients and relatives prefer that healthcare professionals handle the decisions^{23, 30, 31)}. Consequently, a more balanced approach to physician patient communication and medical decision making may be needed for healthcare professionals engaging in ACP.

Rapport building and in-depth interview skills were identified as components for successful person-centered ACP conversation in the study. Rapport, connection, and relationships are key components of the healthcare communication process. These fundamental skills help promote understanding among healthcare professionals, build mutual trust between the healthcare team and their patients, and allow the parties involved to appreciate each other's feelings and viewpoints^{32, 33}.

The results also suggested that successful person-centered ACP required qualitative data from individual indepth interviews with patients. In-depth interview skills are essential for doctors, especially psychiatrists and palliative care clinicians^{34, 35)}. Social workers receive intensive training in in-depth interviewing techniques as part of their education, and recognize person-centered interviewing with their clients as their responsibility within the interdisciplinary care team^{36–38)}. However, physicians tend to prefer dealing with informed consent, which is at the heart of decision making, and are generally ill-prepared to discuss broader aspects such as patients' personal values and preferences³⁹. Informed consent is a recommended approach to medical treatment decisions in which physicians inform patients about the nature, course, and prognosis of the disease and available treatment options; ascertain that they understand their choices; and secure patient-centered care⁴⁰⁾. The effectiveness of physicians' communication skills has proven to be closely correlated with overall patient satisfaction⁴¹⁾, and the results of this study confirmed that formal training in person-centered communication skills for physicians would be highly beneficial. Many physicians find it difficult to get involved in ACP because of heavy workloads, inadequate training, and a lack of time or motivation, and they often neglect in-depth interviews with their patients even though these are essential to the ACP process^{3, 42, 43)}. Therefore, the tangible and achievable targets of person-centered ACP education for physicians are the basic principles of person-centered communication: practicing active listening, showing empathy, and paying attention to the non-verbal components of communication.

Conflict is a significant and recurring problem in endof-life care cases because perceptions of ethical dilemmas vary considerably among healthcare professionals^{44,} ⁴⁵⁾. This study indicated that a better understanding of the differing perspectives of interprofessional healthcare professionals, patients, and families regarding the sources of conflict and serious disagreement in end-of-life might foster the more effective management of difficult situations. Previous literature suggested that the learning and practical experience of interprofessional teams working on common goals to improve patient outcomes increased understanding, shared values, and respect for the roles of other healthcare professionals^{46, 47)}. For example, interprofessional case conferences with end-of-life case scenarios involving sensitive moral and ethical issues improved healthcare professionals' communication and conflict resolution skills³⁸). In clinically

and ethically difficult cases that need to be resolved quickly, there are usually multiple factors to consider including patients' values and preferences, and relatives' concerns and values. In these situations, interprofessional case conference participants could resort to a widely used systematic approach such as the four topics approach to clinical ethical case analysis described by Jonsen *et al.*⁴⁸⁾ to collect necessary data and ensure the success of the conflict resolution strategy.

Conclusion

Successful ACP is beneficial because it supports and improves patient autonomy and dignity, and leads to greater satisfaction on the part of families and healthcare professionals. Even though ACP education programs for lay people are readily available, very few focus on clinical practice guidelines for effective communication regarding ACP. This

study provided new information about guideline topics for improving person-centered ACP: placing the highest value on patient autonomy and human life; uncovering patients' true feelings and desires; sharing collected information on patients' end-of-life wishes with other team members; relaying patients' wishes to physicians; and handling conflicts among patients, relatives, and healthcare professionals. These results offer guidelines for the future development of novel, value-based, person-centered ACP practice for multidisciplinary healthcare professionals.



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