Appraisal of Advance Care Planning within a "Five-Goals-Oriented" Framework

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Contents

Abstract

Background: Advance care planning (ACP) is a recent widespread concept among healthcare providers to support the decision-making process of patients towards their end-of-life. With growing interest in ACP, many studies have been conducted; however, little is known about the goals of ACP. A previous report has described five underlying goals represented in ACP studies; however, the evaluation of ACP is still under development, and the ACP process in its entirety has not yet been elucidated. Thus, the objectives of this review are to identify the current research trends within the scope of a "Five-Goals-Oriented" framework and to examine the studies within each goal to gain insight into the important components of ACP intervention and evaluation. **Methods:** A literature review was conducted using PubMed, EMBASE, and Cochrane Library. Articles published in English between January 2017 and May 2020 that have examined ACP related surveys or interventions in adults and elderly were included. The aforementioned five goals described in a previous report were used to synthesize the research findings. ACP components were extracted from the studies pertaining to each goal and an ACP conceptual diagram was created. **Results:** In total, 3,907 articles were identified, of which the first 123 articles were screened, and 32 articles were finally included. Seven articles (21.9%) were identified as related to *goal 1: Respecting individual patient autonomy*, 13 articles (40.6%) to *goal 2: Improving quality of care*, 3 articles (9.4%) each to *goal 3: Strengthening relationships* and *goal 4: Preparing for end-of-life*, and 6 articles (18.8%) to *goal 5: Reducing overtreatment*. The ACP conceptual diagram assembled from the studies can be divided into three stages: Pre-, Intra-, and Post-ACP Intervention. Although the main process of ACP included having discussions and documentation, and ACP research trends did show weaknesses in addressing the process of communication, the

results showed that ACP encourages patients to have autonomy. ACP is, however, currently limited in capturing the patient's *change* in preferences. **Conclusion:** ACP may be suitable for people who have high autonomy, and/or prefer discussions and documentation. However, ACP research has not captured patients holistically, and has shown limitations in reflecting patient's change of preferences and thoughts. Further research to better understand the process of communication in ACP and patient decision-making is necessary and expected.

I. Background

Advance care planning (ACP) is a recent widespread concept among healthcare providers to support the decision-making process of patients towards their end-of-life. In recent years, there has been increased interest in ACP in many countries, including in medical facilities and nursing homes specifically. In fact, the number of published articles on ACP has rapidly increased over the past three decades – from 151 in 1990 to 889 in 2019. Most articles are from North America, Western Europe, and Australia (1), but the numbers are also increasing in Asian countries. However, the outcomes examined across ACP studies vary.

The definition of ACP, along with the needs for disseminating this concept, has been widely discussed. An initial report from Teo et al. defined ACP as follows (2):

> "...a process of communication that aims to ensure that clinical care is consistent with patients' preferences for care."

In 2017, two studies examined the definition of ACP. First, Sudore et al. defined ACP as follows (3):

> "...a process that supports adults at any age or stage of health in understanding and sharing their 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 illnesses."

Second, the European Association for Palliative Care provided a brief definition of ACP as follows (4) :

> "Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate."

What these three definitions have in common is that they define ACP as a process of communication or decision-making between patient, family, and healthcare providers, with the purpose of ensuring that clinical care or future medical care is consistent with the patient's values, goals, and preferences.

Over the past decades, ACP has often been understood as synonymous with the concept of advance directives (ADs). ADs (including living wills and durable powers of attorney) include the documentation of patient's views regarding specific life-prolonging treatments, such as cardiopulmonary resuscitation, ventilation, or other medical interventions in defined conditions, and/or designating a proxy decision-maker for any decisional incapacity in the future. To increase the completion rate of these ADs, the ACP concept has been developed to support the patient's decision-making process.

Previous studies have shown that ACP intervention could improve the occurrence of end-of-life care discussions between patient and healthcare providers and the completion of ADs (5). Also, ACP intervention could help to align the patient's care preferences with the actual care delivered (5), and contribute to ADs utilization rate among patients. If ADs are not completed, a family may be required to make decisions for the patient when a crisis occurs, and this could result in significant burden to the family (6). ACP discussion(s) could provide some understanding in terms of the patient's preferences or wishes and ease the family in making such decisions, if necessary (7).

Although a large number of studies have addressed the process and definition of ACP, further clarity is needed to reach consensus on the goals. Collectively, these studies have limitations as they represented heterogenous outcome measurements; some

examined a patient's quality of life, satisfaction, and quality of end-of-life (8), while others examined the relationship between ACP intervention and healthcare utilization practices (9). To better understand the underlying goals represented by the heterogeneous outcome measurements, Fleuren et al. (10) in their study identified five underlying goals among the ACP studies. The five underlying goals were as follows: (a) Respecting individual patient autonomy, (b) Improving quality of care, (c) Strengthening relationships, (d) Preparing for end-of-life, and (e) Reducing overtreatment. According to Fleuren et al., these five goals carry equal weight, with each comprising additional subset of goals. Exerting all efforts to achieve each goal (as well as striking a balance between these goals) should be the aim of ACP intervention in practice. In research, these five goals could serve as a foundation for developing a comprehensive method of ACP intervention and subsequent measurement of its effects. However, the measurement of the effects of the ACP is still under development, and the ACP process in its entirety has not yet been elucidated.

The objectives of this review are to identify the current research trends within the scope of a "Five-Goals-Oriented" framework and to examine the studies within each goal to gain insight into the components of ACP intervention and evaluation. After categorization using the "Five-Goals-Oriented" framework, a model ACP study will be

proposed based on this assessment. This review was approached with the underlying hypothesis that ACP interventions can improve the quality of communication between patient, family and healthcare providers, and the important components and evaluation approaches of this process will be extracted.

II. Methods

A literature review was conducted utilizing published articles. First, the articles were identified through a comprehensive search and a list of identified articles was assembled. Second, articles were removed if they did not meet the inclusion criteria. Finally, articles were categorized into the five goals, and data synthesis was conducted using a "Five-Goals-Oriented" Framework to build an ACP research conceptual diagram.

1. Literature Search

A comprehensive literature search was conducted using PubMed, EMBASE, and Cochrane Library in June 2020 using topic-specific keywords (Table 1.1-1.3). Since the definition of ACP was widely disseminated in 2017, articles that were published in English between January 2017 and May 2020 were included for this review to gain insight into the current research trends. Duplicate articles identified across the databases were excluded after data extraction.

Table 1-1 Search strategy used in PubMed

No.	Search Term(s)	Items found
1	'advance care planning'	10490
	Filter: MeSH Terms, Title/Abstract	
2	'Adolescent' OR 'Child' OR 'Infant'	3543005
	Filter: Mesh Terms	
3	#1 NOT #2	9967
4	'case reports' OR 'personal narratives'	6882
	Filter: MeSH Terms	
5	#3 NOT #4	9935
6	Filter: publication date from 2017/1/1 to 2020/5/31	4311686
7	#5 AND #6	1876

Table 1-2 Search strategy used in EMBASE

No.	Search Term(s)	Items found
1	'advance care planning'/exp OR 'advance care planning'	5264
2	'adolescent'/exp OR 'adolescent' OR 'teenager' OR 'child'/exp OR 'child' OR 'children'	4562519
3	#1 NOT #2	4841
4	#3 AND ('article'/it OR 'article in press'/it OR 'review'/it)	2907
5	#4 AND [1-1-2017]/sd NOT [1-6-2020]/sd	1616
6	'case report'/exp OR 'case report' OR 'narrative review'/exp	2607759
7	#5 NOT #6	1577

Table 1-3 Search strategy used in Cochrane Library

No.	Search Term(s)	Items found
1	'advance care planning' OR 'advance care planning' [Mesh]	676
2	'Child' [Mesh]	55053
3	#1 NOT #2	674
4	'Adolescent' [Mesh]	102500
5	#3 NOT #4	654
6	'Infant' [Mesh]	31588
7	#5 NOT #6	654
8	#7 with publication date Between Jan 2017 and May 2020	454

2. Study Selection

Table 2 shows the inclusion and exclusion criteria for this review. Articles that had examined ACP related surveys or interventions in adults and elderly were included. Articles studying ADs as a part of ACP, and articles studying palliative care (ACP was considered as one of the important palliative care roles) were also included. All study types (except case reports and narrative reviews) were considered. Studies focusing on children, or focusing only on healthcare providers or family members were excluded.

Table 2 Inclusion and exclusion criteria

Inclusion criteria	
1	Any type of study that has examined ACP related survey or intervention to adults and elderly
2	Systematic reviews and interview studies
3	Articles studying ADs (as a part of ACP) and palliative care
Exclusion criteria	
1	Case reports and narrative reviews
2	Studies examining pediatric or adolescent patients
3	Studies examining only healthcare providers or family members

3. Data Synthesis within a "Five-Goals-Oriented" Framework

The five goals identified by Fleuren et al. (10) served as a basis for synthesis of the study findings. The five goals are *goal 1: Respecting individual patient autonomy*,

goal 2: Improving quality of care, *goal 3: Strengthening relationship*, *goal 4: Preparing for end-of-life*, and *goal 5: Reducing overtreatment*.

Each article was reviewed, and content related to the five goals were independently identified by two reviewers. The identification process was pursued in the following order:

1. finding key terminology in the text relevant to the goal
2. determining the most appropriate goal based on the outcome examined in the study
3. resolving inconsistencies across reviewers by consensus

Although studies may have focused on multiple goals, a single primary goal was determined and used to categorize the articles, and a conceptual diagram comprising the five goals was created. After categorization, articles were critically appraised and important components were identified that described the goals. Finally, these components of each goal were brought together to build an ACP research conceptual diagram for applying the study findings into practice.

III. Results

In total, 3,907 articles were identified through a literature search (the selection process is shown in Figure 1). After duplicates were removed, 2,636 articles remained. The list of articles was ordered by topic-specific keywords, and the first 123 articles were screened. After screening by title and abstract, 72 articles were excluded from the review due to having been published before 2017, published in a language other than English, and/or not meeting the inclusion criteria. The full text was obtained for 51 articles, and 19 articles were excluded for the following reasons: 5 articles focused on studying only medical doctors, 3 articles were study protocols only (and did not report results), 2 articles were narrative reviews, 1 article was an ACP dissemination study, 1 article was a feasibility study with no ACP related outcome, 1 article was a study that investigated end-of-life research priorities, and 6 articles could not be accessed. In total, 32 articles were included in the review.

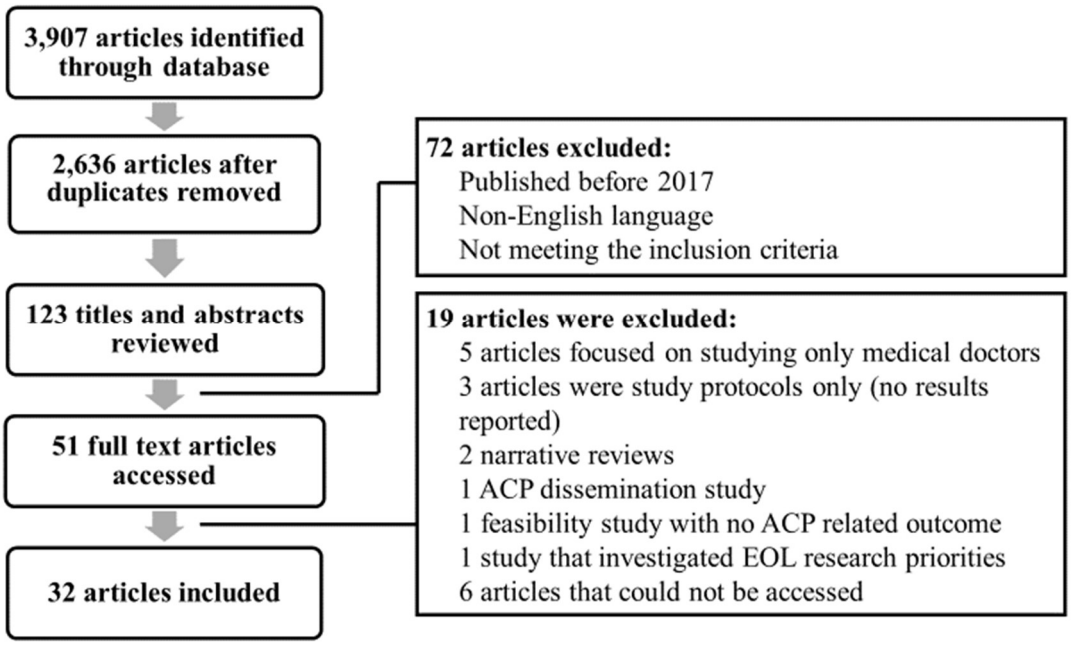

Figure 1. Flow chart demonstrating study screening and selection process

1. Study Distribution and Characteristics

Figure 2 shows the distribution for the number of studies addressing each goal. Seven articles (21.9%) were identified as related to *goal 1: Respecting individual patient autonomy*, 13 articles (40.6%) related to *goal 2: Improving quality of care*, 3 articles each (9.4%) related to *goal 3: Strengthening relationships* and *goal 4: Preparing for end-of-life*, and 6 articles (18.8%) related to *goal 5: Reducing overtreatment*. Overall, the studies represented a range of populations, designs, settings, and findings. The details are shown in Table 3.

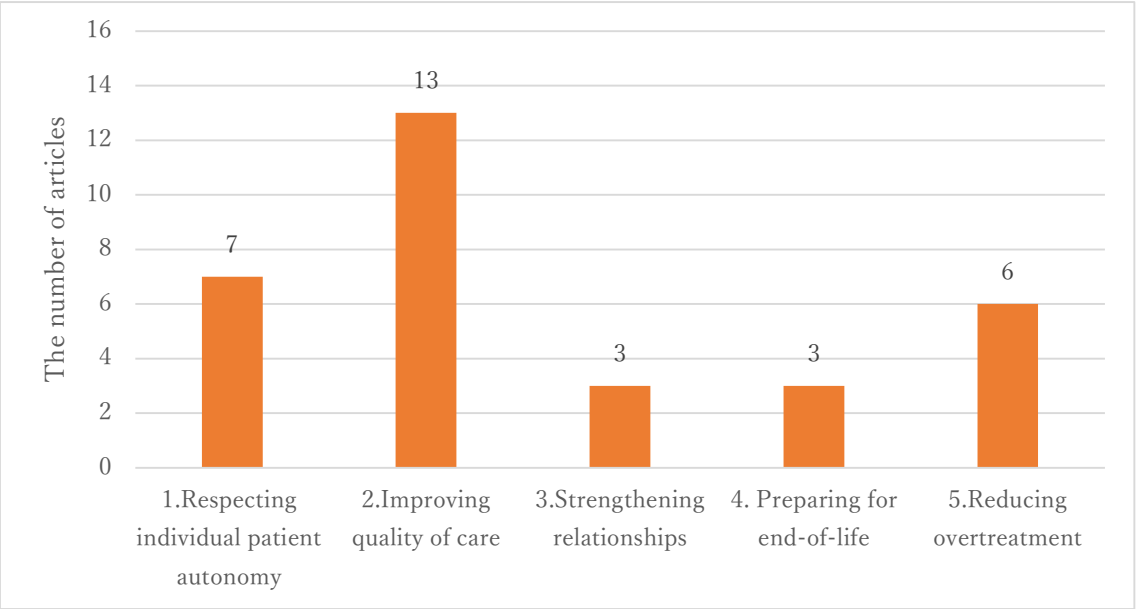

Figure 2. Distribution of articles pertaining to the five goals

Table 3 Study characteristics

Author (year) (ref)	Country	Number of participants /records	Study design	Setting	Description of patients/records	Main findings	Goals
Gieniusz (2018) (11)	United States	197	Retrospective	A hospital	Hospitalized terminally ill patients (estimated life expectancy < 6 months)	Later Goals of Care Discussion were associated with greater risk of aggressive interventions and inpatient deaths, and greater odds of intensive care unit admission.	5
Kurella Tamura (2017) (12)	United States	61541	Retrospective	Nursing homes	Residents receiving maintenance dialysis	Treatment-limiting directives and proxy decision makers were less in place among residents receiving dialysis compared with residents with other serious illnesses (cancer, COPD, and dementia). Among residents with dialysis, having treatment-limiting directives and proxy decision makers were associated with fewer hospitalization, intensive care unit admission, intensive procedures and inpatient deaths, and higher hospice use and dialysis discontinuation compared with residents without those components.	5
Rocque (2017) (13)	United States	2752	Mixed-methods	Cancer centers	Deceased patients with cancer	A navigator-led ACP program may be associated with lower rates of resource utilization (hospitalizations) near end of life.	5
Young (2017) (14)	United States	400	Prospective	Hospitals	Hospitalized patients with acute decompensated heart failure	Patient-reported and clinician-ordered resuscitation preference were discordant in 20% of patients.	3
Bravo (2017) (15)	Canada	470	RCT	Community	Adults (≥70 years old) and their proxy decision makers	The health related quality-of-life ratings were reasonably consistent over time and in good agreement within dyads, even more so as implied cognitive functioning worsened.	3
Verdoorn (2017) (16)	United States	175	Retrospective	A hospital	Patients receiving left ventricular assist devices as a destination therapy (DT-LVAD)	While 70% completed preparedness planning (PP) and 66% of patients completed an AD, only 2.8% AD specifically mentioned DT-LVAD and none addressed core elements of PP. There was a disconnection between the rigor of PP discussions and the content of AD in the medical record.	2

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Deng (2017) (17)	United States	152	Cross-sectional	Outpatient clinic	Adult patients with congenital heart disease	The median rating for the importance of discussing ACP with providers was 7 on a 0-10 scale. Higher ratings for the importance of discussing ACP was associated with female, having lower disease complexity, and having elevated anxiety symptoms. 61% showed the interest in receiving information about life expectancy, and it was higher among patients with lower disease complexity, a history of ≥2 cardiac surgeries.	1
Omondi (2017) (18)	Kenya	216	Retrospective	A hospital	Hospitalized terminally ill patients (estimated life expectancy < 6 months)	Uptake of ADs were 41.2%. Discussion between patient and their physician and patient's functional impairment were the factors independently associated with completion of ADs.	2
Perry (2017) (19)	Canada	200,000*	Retrospective	Long-term care facilities	Residents	Three-quarters of long-term care residents had a directive not to resuscitated and these directives appeared to be well followed; while one in five had a directive not to hospitalize and 7% of these residents was admitted to hospital.	5
Nishiguchi (2017) (20)	Japan	237**	Cross-sectional	Nursing homes	N/A	End of life care bonus has the potential to increase the number of residents receiving end of life care in nursing homes over several years, as well as end of care conferences, physician support for emergency care during off-time, and the presence of an adjacent affiliated hospital.	2
Rodenbach (2017) (21)	United States	170	RCT	Outpatient clinic	Patients with stage III or VI nonhematologic cancers	Intervention group brought up question prompt list (QPL) related topics during their office visit, and nearly three times more likely to ask about prognosis compared with controls. A combined coaching and QPL intervention were effective to help patients with advanced cancer and their caregivers identify and bring up topics of concern during their oncologist visits.	4
Alonso (2017) (22)	Germany	143	Retrospective	A hospital	Patients admitted with a diagnosis of ischemic stroke or spontaneous intracranial hemorrhage	29.4% had a completed and signed written ADs, but only 24.5% were available. Among available ADs, 45.7% described circumstances that is according to the medical life. A majority of patients objected to cardiopulmonary resuscitation (62.9%), mechanical ventilation (54.3%), and artificial nutrition (74.3%), while almost all directed the comfort care (94.3%).	2
Dening (2017) (23)	England	13	Interview	A clinic	Patients with dementia and their carers	Dyads described how decision-making changed after a diagnosis of dementia. Carers recognized increasing responsibility for decision-making after the diagnosis of dementia.	1
Hutchison (2017) (24)	United States	25	Interview	A clinic	Patients with chronic renal failure, clinicians and family members	Readiness for ACP was driven by individual values perceived but a collaborative encounter between clinicians and patients/families. If ACP is not valued, patients and clinicians are delaying conversations until "illness burden necessitates."	1

*The article did not report the actual number of participants, but reported as almost 200,000.

(Continued on next page)

**The number of nursing homes examined in the study

Myers (2017) (25)	United States	N/A	Systematic review	Primary care clinics	Patients ≥ 65 years old	Primary care physicians who emphasize the importance of ADs and who normalize the discussion during office visits by asking questions to understand patients' health goal and holding short conversations over several visits can improve ADs completion rates.	2
Koss (2018) (26)	United States	6861	Cross-sectional	US residents	Non-Hispanic African Americans and Whites ≥ 65 years old	Whites were twice as likely to engage in ACP. Frequency of service attendance was positively associated with ADs completion regardless of race. Among Whites, more frequent prayer was associated with higher odds of advance care discussion.	2
Hirakawa (2017) (27)	Japan	102	Interview	Community	Elderly people receiving home care services	Participants were generally feeling anxious and fearful about the future, but they seemed to avoid thinking too seriously about possible complications in their life. They also tended to leave end-of-life decision to someone else, and their decisions tended to change as they advance in age and as their condition deteriorates.	1
Dayal (2017) (28)	England	22	Retrospective	Hospitals	Patients with multiple system atrophy	The most common topics in palliative care discussions were diagnosis, symptoms or its management, and prognosis. In the majority of patients who died and had a DNR order, discussions of resuscitation and goals of care took place only hours before death.	2
Kamo (2017) (29)	United States	77350	Time series	Outpatient clinics	Patients ≥ 65 years old at oncology, nephrology or primary care clinics	Visits in the intervention primary care clinic were twice as likely to mention ADs in the medical record compared to those in nonintervention clinics. A series of quality improvement interventions to increase discussions about ACP and AD completion in primary care clinics, oncology clinics and nephrology clinics.	2
McQuown (2017) (30)	United States	50	Prospective	Emergency department	Patients presenting from extended care facility to the emergency department	68% had a DNR preference noted in their extended care facility notes, but 28% had a DNR order transported to the emergency department. Only 32% of patient were noted their ADs at registration.	2
Tay (2017) (31)	Singapore	132	Interview	Outpatient hospital	Patients with cancer and their caregivers	Collusion, family-centric decision making, adulteration of information provided to patients, and circumnavigation of patient involvement were context-dependent.	1
Sinclair (2017) (32)	Australia	149	RCT	Hospital/ Clinics	Patients with lung disease	Intervention arm had higher ACP uptake and ACP discussions with doctors compared with usual care. Increased symptom burden and preference for ACP intervention were predictors of later ACP uptake.	2
Milnes (2017) (33)	Australia	482	Cross-sectional	Clinic	Patients at ACP clinic and community-dwelling adults	Living as long as possible was not the most important value for ACP patients, or for a younger general population.	1

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Reinhardt (2017) (34)	United States	300	Retrospective	Nursing homes	Decedents at nursing homes	Almost all decedents had DNR and Do Not Intubate orders in place, and just over one-half had Do Not Hospitalize and No Artificial Feeding orders in place.	2
MacKenzie (2018) (35)	United States	1257	Retrospective	Hospice	Patients with heart failure and cancer	Post propensity score matching showed the trend of using emergency services use among heart failure were higher compared with patients with patients. Discharge to hospital was not significant among two cohort patients.	5
Gilman (2017) (36)	United States	128	Cross-sectional	Clinic	Patients receiving dialysis	68% agreed they were prepared for what to expect; 35% pf patients reported being offered supportive care without dialysis; 82% recalled a discussion about prognosis; 43% completed an AD, but 72% thought it was at least "very important" to plan for the end of life.	4
Friedewald (2018) (37)	Australia	100	Cross-sectional	N/A	Residents (data from electronic medical record at the Central Coast Local Health District)	Only 50 advance care directives were assessed as being valid to inform clinical scenarios. Multiple templates with different designs and of varying length had been used.	2
Sanders (2018) (38)	United States	20	Interview	Prisons	Patients ≥ 60 years old, frail, and less than 1 year life expectancy	6 themes were identified: decisions in the shadow of the past, what works best for me, feeling blessed, what is really going on, can anyone be trusted, and turning agency over to someone else.	1
Portanova (2018) (39)	United States	7177	Retrospective	N/A	Decedents (data from the Health and Retirement Study)	46% had completed an AD (Whites 51.7%, Hispanics 18.0%, Blacks 15.0%). Blacks had 75% lower odds of completing an AD and Hispanics had 70% lower odds. The odds of having an AD increased with each subsequent death year for Blacks and Whites but not Hispanics.	2
Fairlie (2018) (40)	England	234	Cross-sectional	Community	Residents aged 50 ≥ years old	No difference was found in the total Decisional Conflict Scale based on the "Allow Natural Death (AND)" and "Do Not Resuscitate (DNR)", however AND respondents perceived their decision as a good decision and were eight times more likely to sing the document than DNR patients.	4
Russell (2017) (41)	United States	9190	Retrospective	Hospice	Residents at a hospice	Roughly one in five (21%) patients discharged alive, and the most frequent reason for it was acute hospitalization (42%). Acute hospitalization was higher among younger patients, racial minorities, and patients without ADs.	5
Fried (2017) (42)	United States	700	Cross-sectional	Clinic	Community-dwelling Veterans ≥ 55 years old and their surrogates	Over 40% dyads agreed that the Veterans had not completed a living will or health care proxy and that there was no quantity of life (QOL) communication. In dyads who agreed QOL communication had occurred, 30% surrogates had knowledge, compared to 21% dyads agreed communication had not occurred and 15% in dyads who disagreed.	3

2. Proportion of Articles Specific to ADs and ACP Components

Eleven articles (34%) were found to have specifically studied ADs among the ACP articles (although the term "AD" was not queried) (12,14,18,19,22,25,29,30,34,37,39). Figure 3 shows the proportion of articles that addressed ADs specifically, including life-sustaining treatment orders, such as do-not-resuscitate (DNR) or do-not-hospitalize (DNH), as a part of ACP.

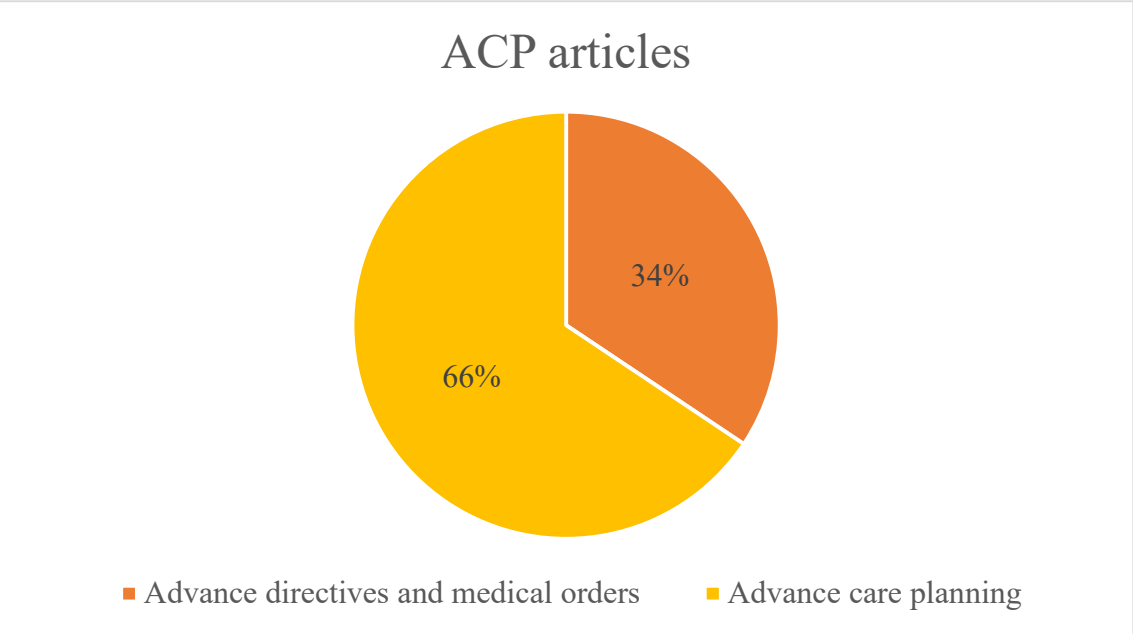

Figure 3. Proportion of articles specific to ADs and medical orders

Table 4 shows the list of ACP components for each goal extracted from studies, and Figure 4 shows the conceptual diagram comprising the extracted ACP components.

Table 4 ACP components for each goal

	Extracted ACP Components	Goal
1	**Priority** **Belief** **Readiness** **Wish**	Respecting individual patient autonomy
2	**Personal factors** **Discussion** -Open-ended questions -Brief discussion time -Multiple opportunities -Early Exposure/Experience **Documentation** **Concordance** -Review occasionally -Validated format -Individualized content	Improving quality of care
3	**Agreement**	Strengthening relationships
4	**Individualized communication** **"Allow natural death"**	Preparing for end-of-life
5	**Resource utilization**	Reducing overtreatment

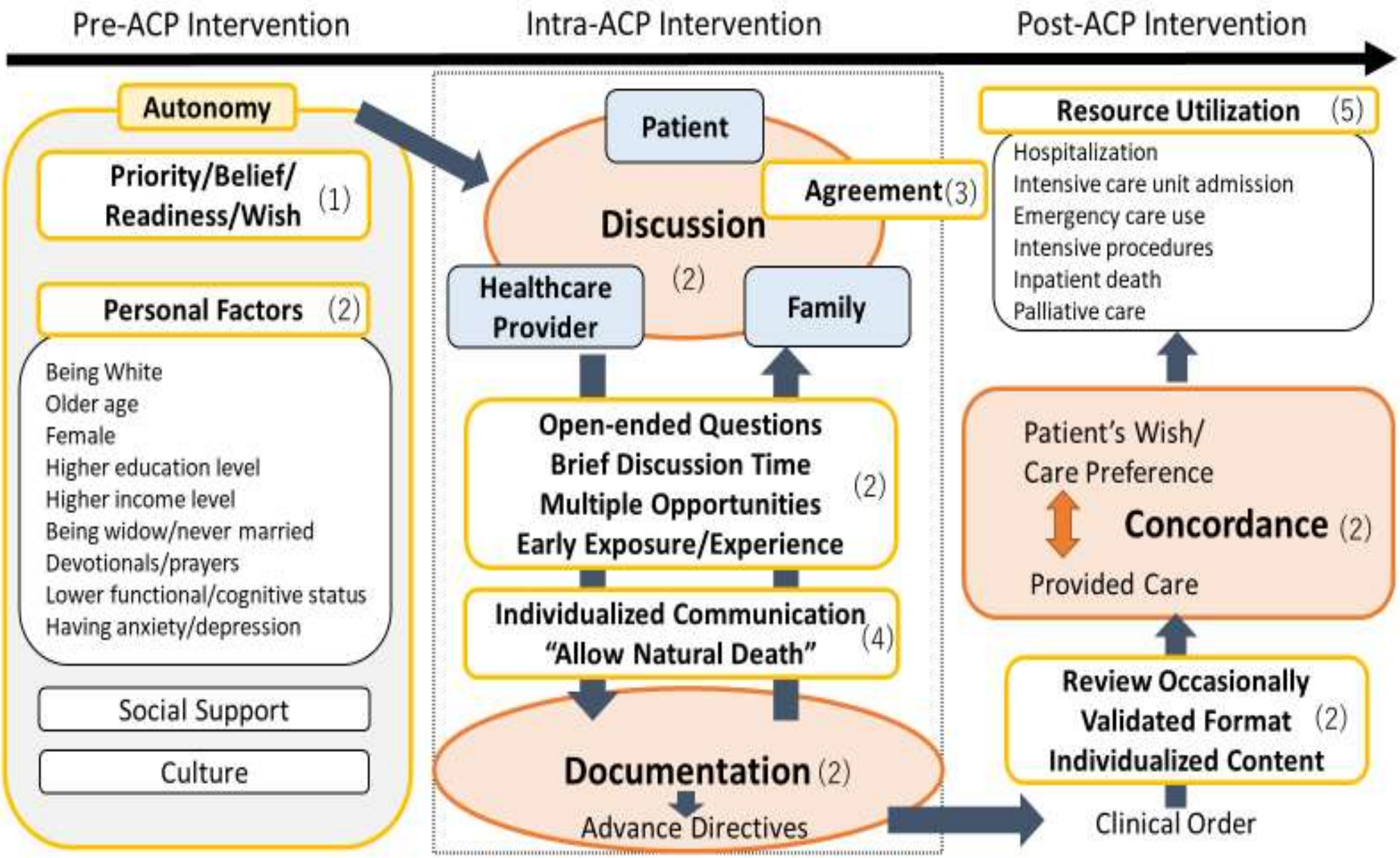

Figure 4. ACP conceptual diagram

*( ) indicates the number of the ACP goal (1-5) from which the component was extracted

3. Descriptions of the Five Goals

After categorizing the 32 articles based on the 5 goals, the important components were identified by finding the key words that repeatedly appeared in the article related to each goal (Table 4). The detailed results can be summarized as follows (Figure 4).

3-1 *Respecting individual patient autonomy (goal 1)*

Seven articles were identified as related to *goal 1: Respecting individual patient autonomy* (17,23,24,27,31,33,38). The main component found in goal 1 was identifying patient's "priorities, beliefs, readiness and wishes/preferences", which was observed in many studies, and some studies focused on the decision-making process itself.

3-1-1 Patients' priorities, beliefs, readiness, and wishes/preferences

Having dignity, being independent enough to retain the current lifestyle and having a sense of control over their decision-making process were found to be the basic wishes, needs and priorities for patients. However, readiness to initiate ACP varied among patients. Not everyone expressed their end-of-life wishes and/or preferences, and

some expressed a fatalistic outlook and were relying on their families to make the decisions for them at their end of life.

Among four categories (dignity, longevity, pain and suffering, and independence), the patients at ACP clinics and community-dwelling adults rated longevity as the lowest priority, while dignity, pain and suffering, and independence were rated as more important for them (33). As age increased, the priority of pain and suffering decreased, while the priority for independence increased (33). Being independent was also found to be important among community-dwelling elderly people. They expressed the importance of being able to perform daily living activities and of maintaining their current lifestyle (27). Patients in another study also expressed the importance of independence, as well as maintain a sense of control (38).This study found that ACP discussion, documenting their end-of-life wishes, and identifying a proxy decision-maker provided patients with a greater sense of control over their decision-making process, and also empowered their feeling that their wish would be honored.

However, the readiness to initiate ACP differed among studies. Among the adult patients with congenital heart disease, close to 80% of the patients preferred to have ACP discussions while they perceive themselves to be “healthy,” and only 1% of

patients preferred it to be at their end of life (17). This study also found that the recognition of the importance of an ACP discussion was higher among patients with stronger anxiety. Additionally, a lower disease complexity was associated with a desire for getting information about their life expectancy. In contrast, patients with renal failure stated that ACP is most relevant close to their end of life when the illness burden necessitates it (24). The readiness of ACP depended greatly on the disease diagnosis, disease complexity, and patient's anxiety level.

Moreover, significant differences were found in terms of end-of-life wishes and/or preferences. Some patients expressed the desire of not wanting life-sustaining treatments and some expressed the desire of wanting them (38). Among community-dwelling elderly people, half of them had a clear opinion regarding treatment, and the other half did not know what was best for them or had no opinion about it (27). Most of them expressed their wish to remain at home for as long as possible; however, they also wished to be transferred to a hospital at the end of life and not to impose on family members (27). Some studies also found that patients had fatalistic outlooks on their future and beliefs of having no control over their death (24,27). In parallel, patients were trusting in the support from their family and felt no need for ACP (23,24). Among patients with dementia, preferences included stepping down from decisional

responsibilities and relying on family to make decisions (23). In summary, some had clear opinions, some did not know what would be the best, some had fatalistic outlook, and some were relying on their family for the decision-making.

3-1-2 Family as a proxy decision maker

For some families, having ACP discussions with the patient and engaging in a shared decision-making process may be important. This allows the family to preserve the dignity of the patients, to protect the patient from harmful information/situations, and to prepare the family to be a proxy decision-maker in the future (23,24,31). As mentioned previously, some patients were relying on their family to make the decisions at their end of life. Another study conducted in Asia found that family-centric decision-making, instead of relying on patient-autonomous decision-making, was context dependent (31). The patient's family were more or less aware of their responsibilities as the future proxy decision-makers and perceived ACP as important.

3-2 *Improving quality of care (goal 2)*

Thirteen articles were identified as related to *goal 2: Improving quality of car*e (16,18,20,22,25,26,28-30,32,34,37,39). The main components found in goal 2 were

“personal factors” associated to ACP uptake, ACP “discussion” and “documentation”, and “concordance” between patient’s preferences and care delivered. In the studies, quality of care was mainly measured by ACP uptake rate. The concordance between patient’s care preferences and the care delivered was also examined as a part of quality improvement.

3-2-1 “Personal factors” associated to ACP uptake

ACP discussions or AD uptake rates were often used as an outcome measurement, and the factors related to having ACP/ADs were examined. The factors that tended to be associated with positive relationships with ACP/ADs were as follows: being White, older age, female, higher education level, higher income level, being widowed/never married, devotionals/prayers, lower functional/cognitive status, and having anxiety/depression (18,26,32,34,39). The factor associated with a negative relationship with ACP/ADs was being non-White (African Americans and Hispanics) (26,39). ACP discussions and/or ADs were more popular among White subjects.

3-2-2 ACP “discussion” and “documentation”

Discussion and documentation were main components in the ACP process. When initiating ACP discussions, open-ended questions allowed the patients to express their feelings and thoughts and help the healthcare providers to identify the possible barriers (25). Then, having short discussions between the patient and the healthcare providers over multiple occasions was important to increase the ADs completion rate (25,29,32). Initiating ACP discussions at a general health check-up normalized the discussion, helped to establish trusting relationships between patients and healthcare providers, and increased the patient's satisfaction with the healthcare providers. It also provided time and opportunities for patients to reflect on their goals, future health care needs, and preferences (25). After the discussions, documenting the discussion contents was found to be important. In most of the cases, this documentation was considered as ADs and treatment specific orders. Then, the orders should be reflected when the situation necessitates it, however, one study argued that the order was less likely to be transferred between healthcare facilities without a standardized format (30).

3-2-3 "Concordance" between patient's care preferences and care delivered

After the documentation is obtained, maintaining the concordance between the patient's care preferences and the care delivered is essential to maintain the quality of

care. Thus, the quality and validity of documentation were examined in some studies. Concerns with the validity of the documentation process included having no witness and/or not using a standardized format (22,30,37). Using a standardized format can reduce validity concerns, but ensuring its quality was pointed out as a limitation in one study. A standardized format may be less likely to reflect the individualized context of a patient's preferences (22). Another limitation of documentation was that they are required to be updated or reviewed overtime. Without reflecting any updates of patient's preferences, its quality and validity come into question (22,37). Concordance should be updated and reviewed regularly.

3-3 *Strengthening relationships (goal 3)*

Three articles were identified as related to *goal 3: Strengthening relationships* (14,15,42). The main component found among studies in goal 3 was "agreement" between patients and their families, and between patients and healthcare providers.

Strong communication is necessary for understanding patients. In the studies, agreement rates between the patient and their family/healthcare providers were often measured to evaluate concordance. One study that examined the concordance between the patient and healthcare providers found that there was about 20% discordance in

patient's stated treatment preferences and healthcare provider's medical orders (14). This discordance could be a reflection of patient's indecisiveness and/or miscommunication between the patient and the healthcare providers, but further exploration was required. On the other hand, in situations where both the patient and the proxy decision-maker were perceived to have communicated, the proxy decision-makers had a better understanding of patient's health status (42). Another study showed that the proxy decision-makers were relatively accurate in predicting patient's health-related quality of life and the ratings were found to be consistent over time (15). Good communication requires recognition and understanding from both agents. The proxy decision-maker may be able to reflect the patient's preferences/wishes when needed; however, it is not possible without good communication between them.

3-4 *Preparing for end-of-life (goal 4)*

Three articles were identified as related to *goal 4: Preparing for end-of-life* (21,36,40). The main components found among studies in goal 4 were "individualized communication" and usage of the phrase, "allow natural death" (as opposed to "DNR").

3-4-1 “Individualized communication” by social workers

Providing individualized communication encourages the patient and/or their family to bring up ACP discussion and leads to better understanding of the patient’s condition. One study showed that offering “Individualized Communication Coaching” to a patient and his/her family using a question prompt list increased the discussion occurrence rate from the patient to healthcare provider (21). Patients were able to bring up various topics, such as their health expectations/prognosis, current health state, goals of treatment, symptom management, and preferences/concerns about care at the end of life.

3-4-2 Usage of the phrase “allow natural death”

Beyond simply communicating patients’ wishes, word choice is also important. One study showed that the phrasing “allow natural death” was more accepted among individuals than “DNR” (40). It was found that “allow natural death” could lead the family to perceive their decision as a “good” decision. The study also found that experienced decision-makers (e.g., those who already completed their own ADs or served as a proxy decision-maker for their own family) had clearer ideas about the

patient's personal values, benefits, and risks of signing documents. They also perceived their decision as a "good" decision – even more when "allow natural death" was used.

3-5 *Reducing overtreatment (goal 5)*

Six articles were identified as related to *goal 5: Reducing overtreatment* (11-13,19,35,41). The main component found among studies in goal 5 was "(health care) resource utilization." ACP has an impact on health care utilization. Many ACP interventions resulted in decreasing health care utilization, and several studies examined the factors associated with increased health care utilization. The main outcomes that were measured among studies were hospitalization, intensive care unit (ICU) admission, emergency care use, intensive procedures (e.g., intubation, CPR, and chemotherapy use), inpatient death, and palliative care related outcomes (such as hospice use and dialysis discontinuation).

3-5-1 Decreasing "resource utilization"

The interventions found to decrease health care utilization were training a designated healthcare provider to conduct ACP discussions, initiating ACP discussions at earlier timing, and having ADs. One study that introduced an ACP navigator in health

care facilities reported lower hospitalization rates among patients who had ACP discussions with the navigator (13). Certain trends related to the use of the navigator were also observed: less chemotherapy use, less emergency care use, and fewer ICU admissions (13). Another study found that initiating goals-of-care discussions between patients and physicians earlier were associated with less aggressive intervention, lower risk of inpatient death, and lower odds of ICU admission (11). Meanwhile, the residents with DNH orders in long-term care facilities were about half as likely to be hospitalized as residents without DNH orders (19). ADs among nursing home residents receiving maintenance dialysis were also related to fewer hospitalizations, fewer ICU admissions, fewer intensive procedures, and fewer inpatient deaths compared to patients without ADs (12).

3-5-2 Increasing "resource utilization"

In addition, factors associated with increased health care utilization were examined in several studies. In one study, higher emergency care use was associated with a primary diagnosis of heart failure (as compared to cancers), longer length of hospice stay, having more comorbidities, having no documented ADs, living in rural areas, and living in for-profit hospices (as compared to nonprofit hospices) (35). In

another study, acute hospitalization was associated with non-whites, unmarried patients, having no ADs, patients with specific health insurance, patients with non-cancerous disease (e.g., dementia, heart failure, and pulmonary disease), and having a higher palliative performance scale (41). Furthermore, patients with ADs tended to have more hospice use and more dialysis discontinuation (12).

IV. Discussion

This review aimed to identify the current research trends and gain insight into the important components of ACP. The conceptual diagram assembled based on the observations from the studies can be divided into three stages: Pre-ACP intervention, Intra-ACP intervention, and Post-ACP intervention.

1. Pre-ACP Intervention

Goal 1: Respecting individual patient autonomy took priority in this stage. The main components of Pre-ACP intervention were identifying "patient's priorities, beliefs, readiness, and wishes/preferences" (goal 1) and "personal factors" associated with ACP (goal 2).

The results showed a variety of patient's preconditions (e.g. longevity, keeping dignity and independence, sense of control, and fatalistic outlooks). Assessing these preconditions before ACP intervention was found to be essential to support the patient's autonomy and autonomous decision-making. However, the results also showed that some patients did not consider autonomous decision-making as critical; rather they depended on their family and/or care providers or had a belief of no control over their

death (23,24,27). This suggests that not all patients prioritized autonomy or autonomous decision-making.

Another implication from the study results was that autonomous decision-making may only be available while they perceive themselves to be healthy (17,23). Recently, ACP has expanded from advanced decision-making to “in-the-moment” decision-making. This allows the patient and their family to be involved in making concurrent healthcare decisions, and to better prepare for end-of-life decision-making (43). This approach can be drawn from the results acknowledging that not everyone has an autonomous decision-making style, and the decision-making style can even change as the health condition deteriorates.

Furthermore, having strong social support (such as family) and cultural backgrounds have influence over patient’s autonomy and commitment to ACP (18,31,32,39). Although the influence of having family differed among the studies, it is clear that family plays an important role in ACP. The relationship between the patient and family, as well as their cultural background, should be considered in any ACP intervention.

2. Intra-ACP Intervention

Taking priority at this stage were *goal 2: Improving quality of care*, *goal 3: Strengthening relationships*, and *goal 4: Preparing for end-of-life*. The two main components at the Intra-ACP intervention stage were having "discussions" between the patient, family, and healthcare providers (goal 2), and "documentation" about the discussion(s) (goal 2). The cues for initiating ACP discussion(s) were "open-ended questions," "brief discussion time," "multiple opportunities," and "early exposure/experience" (goal 2). The cues for communicating with patients were forming "individualized communication" and the phrasing "allow natural death" (goal 4). These could lead to better communication between the patient, family, and healthcare providers, and lead to "agreement" in the patient's treatment preferences (goal 3). This process could lead to the fulfillment of ACP documentation, such as ADs (goal 2).

The results showed that the ACP studies focused more on documentation than the process of communication. The most commonly evaluated outcome was the uptake rate of ACP documentation, such as ADs. Furthermore, patients' preferences observed in the results were mostly related to life-sustaining treatments, and it was mostly "do not" orders rather than "do" orders (e.g. "DNR" vs. "do resuscitate"). Discussing particular life-sustaining treatment(s) was related to having a "do not" order with the

treatment in place (34). This trend highlights the concern of whether ACP discussions truly reflect the patient's wishes and preferences. Another study pointed out that current ACP intervention was perceived as a "documentation and filing-away" task and not as a comprehensive reflection about their life choices (24). These results may show the reality of ACP, which is still under development as a process of communication. The results suggest that ACP research needs to pay more attention to the process of communication and how ACP can better reflect the patient's wishes, beliefs, and life goals.

Another point is that there is a "gap" between the patients' perception and behavior. Recognizing the importance of ACP does not always correspond to ACP uptake (36). Patients were expecting to be in the same or better health condition and were generally optimistic about the condition of their health. This may relate to the completion rate of ADs, which was less than 50% in many studies. Being optimistic and/or having difficulty to think about "what-if" situations may be a more common reality for patients. Further research is required to better understand this phenomenon.

Governmental financial support can impact the implementation of ACP. One study showed that governmental financial support (end-of-life care bonus) facilitated the development of an organizational procedure or multidisciplinary care program (20).

Having ACP discussions with patients was one of the criteria to receive some disbursement of an end-of-life care bonus. The results showed an increase in the occurrence of end-of-life care conferences, as well as the establishment of a system such as physicians' support for emergency care during off-time and the cooperation among health care facilities. Policy-level interventions can be a fast and powerful way of spreading ACP among healthcare facilities. However, policy implementation may confuse the front-line healthcare providers. One study showed that even among healthcare providers, the meaning of ACP varied and some thought ACP was associated exclusively with death or dying instead of "planning for and achieving quality of living at and before end of life" (24). The needs identified by the front-line healthcare providers and organizational leadership are required to enhance ACP through a policy approach (29). Furthermore, without the needs detection and organizational corroboration, ACP policy could raise some ethical dilemmas among patients, family, and healthcare providers.

3. Post-ACP Intervention

Taking priority at this stage were *goal 2: Improving quality of care* and *goal 5: Reducing overtreatment*. The main components were maintaining the "concordance"

between the patient's care preferences and care delivered. After documentation was obtained, clinical orders would be in place referring to ADs (goal 2). To maintain the concordance between them, using the "validated format," including "individualized context," and "occasionally reviewing" the documentations are considered crucial (goal 2). Furthermore, this concordance is also measured to see the change in "resource utilization" according to ACP (goal 5).

To realize patient's preferences, detailed communication about the possible treatment between the patient and healthcare providers is necessary. The patient may be able to state "DNR" or "do not intubate," but it might be difficult for them to fully understand the exact circumstances in which to use these terms. One limitation of ADs was a lack of a precise description of detailed applicable scenarios (22). If the purpose of ACP is to understand the patient and build a relationship between the patient, family, and healthcare providers, the longitudinal process may help to cover this missing information on the ADs. However, if the purpose of ACP is just to fill out the AD forms, there will be limitations to understand the patient's actual preferences and there could be difficulties in reflecting it. Furthermore, it is important to understand that patient preferences can change over time. An environment that supports a patient to express their feelings and thoughts and that provides occasional opportunities for

follow-up is critical in assuring that the provided care is in accordance with the patient's wishes.

Finally, some studies assessed the concordance of ACP, care delivered and healthcare utilization, and showed that many of the ACP interventions were associated with decreased healthcare utilization. The goal of reducing overtreatment could be a goal for patients who live where healthcare is expensive, or where policymakers are working to reduce overall healthcare costs, but may not be a priority for patients who live where universal health coverage exists. In studies that considered palliative care as healthcare utilization, ACP appeared to increase this use of care. The better goal, according to healthcare utilization, would be "optimizing treatment" for the patient, family, and healthcare providers.

4. Overall

The results showed that ACP encourages patients to have autonomy, but limitations were observed in terms of capturing the patient's possible changes in preferences. The main process of ACP included having discussions and documentation, and according to ACP study trends, less emphasis has been placed on the process of communication. Because ACP focuses on understanding the patient's medical care

preferences in advance, trying to understand the patient's holistic views – including the patient's wishes and life goals – may not be within the scope of ACP. However, understanding the patient's needs holistically is critical in practice, especially with aging societies. With better understanding of patient's autonomy and the process of communication in ACP, expanding the ACP concept broadly from only focusing on the medical care preferences to including patient's wishes and life goals may be needed.

5. ACP trends in Japan

ACP is a rapidly recognized concept in Japan as well. The Ministry of Health, Labour and Welfare disseminated a revised guideline regarding decision-making processes at the end of life, and the ACP concept was included as a main part of the guideline (44). The Japan Gerontological Society also announced their recommendations of ACP promotion in 2019 (45).

In contrast to ACP concepts developed in the U.S., ACP is promoted in Japan as a tool of communication to better understand the patient. And, this tool is used to develop concurrent care planning as well as advance care planning for the future. Although there are currently no regulations governing ACP or governmental disbursement to conduct ACP in Japan, the current rapid attention paid to ACP from

healthcare providers could be the result of a recognized need for supporting patients' decision-making process in practice. Especially in an aging society, more detailed, tailor-made individualized care is required and expected. This Japanese ACP concept could help healthcare providers to better understand patients and their families, and could help to further develop their relationships as well as coordinate their care. However, as experienced elsewhere, there is also confusion among healthcare providers in Japan, and the understanding of ACP varies. It may be because ACP is an originally imported concept, therefore, translations into Japanese may contribute to the ambiguity, and many Japanese terms are already in use to describe equivalents to ACP (e.g. *Zinseikaigi* (人生会議) and *Kyodo-Ishikettei* (共同意思決定)). Furthermore, the limitations that were found in this review are also observed in Japan even though ACP is used exclusively as a communication tool. Not every patient prefers to discuss the details of their wishes or life goals, and even if they share these thoughts, those could change at any moment. ACP is an important tool to better understand patients, but should not be considered a panacea. More engagement with healthcare providers to better understand the Japanese concept of ACP, as well as its limitations, is expected.

6. Limitation

The primary limitation of this study was the limited number of articles included in this review which may not reflect the body of ACP research in its entirety. However, it was possible to assemble an ACP conceptual diagram from the results explaining the important components. Because there were only six articles total for both goal 3 and 4, increasing the number of articles may help to better understand the process of communication in ACP in future studies.

Additionally, because the aim of the study was to identify the current research trends and gain insight into the important components of ACP, a diverse collection of ACP research articles were considered. This resulted in a wide variation of ACP study characteristics. The generalizability of each result may require further consideration in additional systematically conducted efforts. It is possible that the overall conclusions of this synthesis may not apply to certain select populations.

V. Conclusion

ACP may be suitable for people who have high autonomy, and/or prefer discussions and documentation. However, ACP research has not captured patients holistically, and has shown limitations in reflecting patient's change of preferences and thoughts. Further research to better understand the process of communication in ACP and patient decision-making is necessary and expected.

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