

**Let's talk about death, dying, and what matters most
in life**

Target groups, early outcome measurement, and a
gamification approach in advance care planning research

Dissertation

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List of Abbreviations

ACP	Advance care planning
AD	Advance directive
CG	Control group
c-RCT	Cluster-randomized controlled trial
IG	Intervention group
S	Scenario
SPS	Scenario preference score
STADPLAN	Study on Advance Care Planning in care-dependent community-dwelling older persons
TFA	Theoretical framework of acceptability
TP	Treatment preference
TPS	Treatment preference score
TRAPD	Translation, Review, Adjudication, Pretest, Documented
Treat-Me-ACP	Treatment-Preference-Measure-Advance Care Planning instrument
YHP	Young and healthy people

1 Introduction

1.1 Advance care planning

The principle of informed consent is a fundamental requirement to provide medical and nursing care in accordance with the patient's wishes at the national and international levels. Only in exceptional cases, such as acute emergency situations in which the patient's wishes are unknown, healthcare providers may assume that the patient would consent to a life-sustaining treatment without this having been confirmed in advance by the patient or an authorized person (Wilkinson et al. 2007). To ensure that the patient's wishes are respected in as many healthcare situations as possible in which the patient is unable to give consent, it is necessary to know the patient's wishes before such healthcare situations arise, by, for example, obtaining written documentation of the patient's wishes or an authorized person who can make informed decisions about the person's care (Conroy et al. 2009).

To enable patients to document their own wishes in writing, the concept of the advance directive (AD) was introduced for the first time in the US in the 1960s (Benzenhöfer and Hack-Molitor 2009) as "living will" (Kutner 1969). In the 1970s, ADs became the primary tool to formally document a patient's wishes and communicate them to healthcare providers. Until the 1990s and early 2000s, ADs were mainly standardized documents designed to prevent errors and misuse. At that time, there were specifications for phrasings, the structure of the AD, and the appointment of an authorized person (Sabatino 2010).

A 2007 literature review on the use of ADs in the United States revealed that only 18% – 30% had completed an AD (Wilkinson et al. 2007), despite years of advocacy by healthcare providers, government agencies, and legislators to record patients' wishes in an AD (Fagerlin und Schneider 2004). Research made it clear that patients needed more support in documenting their wishes than existing documents could provide (e.g., Hickman et al. 2005; Fried and O'Leary 2008). To address this issue and strengthen patient wishes and patient autonomy, the concept of advance care planning (ACP) emerged in the 1990s and early 2000s (Wilkinson et al. 2007). Although there was no standardized definition for the concept, the focus of ACP was not only on completing legal documents, but also on discussing and communicating the patient's wishes to family members, loved ones, and healthcare providers (Institute of Medicine [US] Committee on Care at the End of Life 1997).

In 2010, there was a call to further expand interpretation of the ACP concept. As it can be

difficult to explicitly define a patient's wishes due to changing circumstances (changing health status, ageing, etc.), ACP should also prepare patients and their family members, loved ones and healthcare providers to make medical decisions when necessary (Sudore und Fried 2010). In 2017, a large Delphi panel finally developed the first standardized definition for ACP:

“Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.” (Rietjens et al. 2017)

Research shows that this definition also has its weaknesses because the focus is on future healthcare decisions only. Hence, there is an approach to reconceptualize ACP in such a way that ACP is part of *care planning* over the entire course of life and consists of both 1) "in-the-moment decisions" (Hickman et al. 2023) that are made for a current healthcare situation and 2) "advance decisions" (Hickman et al. 2023) that are made for the future when the person might be unable to give consent (Hickman et al. 2023). As with the 2017 Delphi Panel definition (Rietjens et al. 2017), two central aspects remain important components of this new conceptualization: 1) ACP is not a one-time process. One's own wishes and preferences should be re-evaluated over time. 2) ACP is a concept for all people. It is not limited to certain age groups, health conditions (except incapacity), or other characteristics (Hickman et al. 2023; Rietjens et al. 2017).

1.2 Advance care planning in Germany

ADs have only been legally anchored in Germany since 2009 (Deutscher Bundestag 2009), though they have been a part of public discourse since the 1970s with reference to the right to self-determination (Art. 2 [1] and Art. 2 [2] sentence 1 of the Basic Law [Deutscher Bundestag 1949]) and human dignity (Art. 1 [1] of the Basic Law [Deutscher Bundestag 1949]) (Deutscher Bundestag 2004). These discussions were intensified by a 1994 ruling by the Federal Court of Justice (Deutscher Bundestag 2004), in which the legitimacy of withdrawing life-sustaining treatment in the case of a terminally ill patient who was no longer able to give consent before dying was confirmed in individual cases. At the end of

the 1990s, the German Medical Association (Bundesärztekammer) described the three ACP documents in its *Principles for Medical Care at the End of Life* including ADs, lasting power of attorney, and guardianship directive, "essential aids" (Bundesärztekammer 1998) for physicians. (Bundesärztekammer 1998) and published a guide for physicians on how to deal with ADs, including their formal and substantive requirements and validity. (Bundesärztekammer 1999). In a 2004 revision of the *Principles of Medical Care at the End of Life*, the ACP documents are described as an opportunity for patients to exercise their right to self-determination (Bundesärztekammer 2004). In contrast to the 1998 version (Bundesärztekammer 1998) the refusal of treatment in an AD is deemed binding (Deutscher Bundestag 2004).

In 2003, the Federal Ministry of Justice established the *Interdisciplinary Working Group on Patient Autonomy at the End of Life* to discuss issues related to the binding nature of ADs, identify key points for the preparation of Ads, and examine whether legal changes are necessary (Arbeitsgruppe "Patientenautonomie am Lebensende" 2004). In 2009, it was finally established that a patient's wishes as expressed in an AD are legally binding (Deutscher Bundestag 2009).

The first ACP intervention was tested in nursing homes in Germany from 2009 to 2011. In this non-randomized controlled study, an increase in the number of ADs was observed. (Schmitt et al. 2014). These results led to the passing of a law in 2015 that enables nursing homes and facilities to offer ACP to their residents at the expense of statutory health insurance (Götze et al. 2023). The details of ACP delivery, including goals, content, quality requirements for providers, and reimbursement, were agreed in 2017 by the National Association of Statutory Health Insurance Funds and the higher-level associations of nursing homes and integration assistance facilities (GKV Spitzenverband 2017). In a cross-sectional survey conducted in 2023, just over half of the nursing homes participating stated that they offer some form of ACP for their residents (Berloge et al. 2024).

Currently, there is no legal basis for the reimbursement of delivering ACP in settings outside care homes and integration assistance facilities. First research projects have been carried out that have examined the effectiveness of ACP interventions in the outpatient care sector (Hoffmann et al. 2023; Bronner et al. 2020), but there are no regulations guiding reimbursement for these settings yet. Although there is no reimbursement for ACP beyond nursing homes and integration assistance facilities, initiatives to empower people to deal with death and dying, and to improve their related competences exist, such as the Caring

Communities in Cologne (Meesters et al. 2024), Göttingen (Koordinationsstelle des Hospiz- und Palliativnetzwerkes n.d.), and Würdevoll Altern und Sterben in der Märkischen Schweiz e. V. (Association for dignified ageing and dying in Märkische Schweiz e.V.) (Würdevoll Altern und Sterben in der Märkischen Schweiz e.V. n.d.).

1.3 Aim

ACP aims to empower all people who can give consent, regardless of age or health status, to address their individual wishes and preferences for medical and nursing care before death/in critical care situations (Rietjens et al. 2017). Based on this definition, the aim of this dissertation is ...

(1) to analyze whether previous ACP research meets the definition of the ACP concept and all people, regardless of age and health status, are given the opportunity to undergo an ACP process;

(2) to translate a low-threshold ACP intervention targeting the general population, adapt it to the German context if necessary, and test its acceptability and comprehensibility;

(3) to develop an early outcome instrument that enables the effectiveness of ACP interventions to be evaluated, even when critical care situations, such as death or loss of capacity to consent, can hardly or not at all be observed due to the duration of the study or the target group.

1.4 Outline

This work consists of three self-contained sections on ACP. The contents and results of these chapters are briefly described below.

Section 2 is a scoping review conducted with Nicola Dymek and Juliane Köberlein-Neu. The review provides a comprehensive mapping of ACP interventions that have been evaluated for their effectiveness and were under study until April 26, 2024 (the day the literature search for the scoping review was updated). The review aims to answer the overarching question of whether the research to date fulfills the definition of ACP in terms of enabling all people – regardless of age and health status – to understand and communicate their wishes and preferences regarding medical and nursing care at the end of life. Thus, the following research questions guided the review:

What are the settings and target populations at patient level in which ACP interventions are implemented?

What are the components of the evaluated ACP interventions?

Was the development of intervention components guided by a theoretical approach, in particular a model, framework or theory?

The results show that until April 26, 2024, ACP research focused primarily on older (60+ years: 30.4%) and/or chronically or seriously ill individuals (65.0%). Only 22.6% targeted healthier (not in need of care and not chronically/seriously) ill individuals. More than half of all the studies (52.7%) were conducted in a hospital or clinical setting. The results demonstrate that previous research did not fully embody the concept of ACP, as not everyone, because of the aforementioned focus of the target groups, has been given the opportunity to undergo an ACP process and express their medical and care wishes and preferences in the event of inability to give consent.

Based on the scoping review's results and the finding that no low-threshold ACP intervention targeting people regardless of age and/or health condition in German-speaking countries was published, *Section 3* describes the translation, adaptation, cognitive pretesting, and piloting of a low-threshold ACP intervention (*Hey du*) for Germany that targets the general public. *Hey du* is a conversation game for groups of two to five players. Players answer 32 questions about their wishes and preferences regarding death and end-of-life care. First, players answer the questions in writing individually, and then they can be presented and discussed in the group.

The study shows that *Hey du* is comprehensible and acceptable. The vast majority (93.7%) of participants reported that *Hey du* helped them to understand their wishes and preferences for medical and nursing care, and 92.1% of participants stated that they felt comfortable while playing the game (Jaschke et al. 2025). This study was a collaboration with Sara Söling and Juliane Köberlein-Neu.

ACP intervention evaluations often focus on long-term outcomes that can be observed and assessed when study participants' health status changes during the study observation period or when they die. Examples of these outcomes include the number of hospitalizations, length of stay, or use of life-sustaining treatments (Brinkman-Stoppelenburg et al. 2014). This type of outcome cannot be used for evaluating interventions targeting the general public or younger and healthier (i. e., not in need of care and not chronically/seriously ill) individuals, such as *Hey du*, because critical care situations, such as the incapacity to consent, occur less frequently in younger/healthier study populations and are therefore less likely to be observed during the course of the study. It is therefore necessary to evaluate these interventions using early outcomes, meaning outcomes that do not depend on a change in health status or death.

Section 4 was written as part of the randomized-controlled trial of the STADPLAN project, which was funded by the Federal Ministry of Education and Research. It was written in collaboration with the STADPLAN project team at the following universities: University of Oldenburg, University of Lübeck, Martin Luther University of Halle-Wittenberg, and University of Cologne.

In this study, the patient-reported instrument *Treatment Preference Measure-Advance Care Planning* (Treat-Me-ACP) was developed based on the Life Support Preference Questionnaires (Bookwala et al. 2001; Coppola et al. 1999) and the Emanuel Medical Directive (Schwartz et al. 2004) and validated in a community-dwelling study population. It uses five hypothetical scenarios and one item on the global medical care goal at two time points, asking whether participants would prefer care or treatment that allows them to live as long as possible, even if it leads to health problems, or care or treatment that could shorten their life but potentially reduce the risk of serious health problems. By using the scenarios the Treat-Me-ACP does not require critical care situations to occur. For each scenario, participants were asked how they would feel (*how would you feel*-item) if they remained in that state of health for the rest of their lives, and they were invited to rate what their treatment preference would be if they required one of five treatments described using a 5-point Likert scale. This instrument enables two types of preference score to be formed: 1) preference scores for treatments within a hypothetical scenario (scenario preference score), and 2) preference scores for a specific treatment across hypothetical scenarios (treatment preference score) (Jaschke et al. 2024).

The study determined the *acceptance* of the Treat-Me-ACP based on the completion rate and frequencies of missing data per item and for the instrument as a whole. *Internal consistency* was determined using Cronbach's α . For *concurrent validation* the association between the global medical care goal item and the scenario preference scores as well as the association between the *how would you feel*-items and the preference scores was determined. The *responsiveness of the instrument to changes in preferences for life-sustaining treatments* was also assessed. The results reflect good psychometric characteristics in terms of the acceptability and feasibility of the Treat-Me-ACP. They indicate that the instrument is appropriate for use as an additional outcome instrument in the evaluation of ACP interventions and the dynamics of medical treatment preferences in ACP (Jaschke et al. 2024).

2 Rethinking Advance Care Planning: A Scoping Review of Target Groups, Settings, and Future Directions

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2.1 Abstract

Background: Advance Care Planning (ACP) was conceptualized to empower individuals, regardless of age or health status, to understand and communicate their preferences regarding end-of-life care decisions.

Aim: This scoping review examines whether research to date aligns with these principles. We analyse the settings and target populations for which interventions are implemented and examine whether these interventions are theoretically guided.

Methods: This review includes studies with a before-and-after-design that evaluate the effectiveness of ACP interventions at the patient level. Data were extracted on target populations, settings, intervention components, and study designs.

Results: Current research deviates substantially from the original conceptualization of ACP: Rather than serving all individuals regardless of age and health status, interventions primarily target older adults who are chronically or seriously ill (65.0%). Most are implemented in hospital or outpatient clinic settings (52.7%), and in nursing homes or assisted-living facilities (12.7%). Just under one-fifth (19.5%) of the included studies reported on the theoretical foundation of the intervention.

Conclusion: The implementation of ACP requires fundamental reconsideration. Rather than developing interventions that only reach individuals after they have become ill or elderly, the field should prioritize population-wide approaches that position ACP as an essential life

competency.

2.2 Introduction

2.2.1 Background

Advance care planning (ACP) – sometimes also called anticipatory care planning [1] – is a concept intended to motivate and empower people, regardless of their age or state of health, to understand and communicate their wishes and preferences regarding medical and nursing care at the end of life. It also encourages them to reflect on such preferences in the event that they are no longer able to give consent. The purpose of ACP is to enable the communication of individuals' wishes and preferences to their loved ones and healthcare providers, and to document these wishes and preferences in writing, e.g. in the form of an advance directive [2]. Importantly, the foundational definition of ACP explicitly includes “adults at any age or stage of health” [2], suggesting that ACP should be a universal process relevant to all members of society, not solely those who are already ill or approaching end of life [2]. This conceptualization positions ACP as a proactive, population-wide approach to healthcare planning that could become an essential life skill and societal competency.

The foundations of today's concept of ACP were laid in the United States in the 1960s, when the concept of advance directives (at that time called a living will [3]) was first discussed [4]. In the beginning, advance directives were primarily standardized legal documents with predefined, mandatory phrases that gave less flexibility to the person completing them. This has resulted, for example, in many people not taking advantage of the opportunity to complete an advance directive, difficulties in comprehending the documents and the implications of their completion, and a paucity of support available to those seeking to complete them. [5].

Building on this, the concept of ACP emerged in the 1990s and early 2000s [5], focusing not only on completing legal documents, but also on discussing and communicating wishes and preferences [6]. Since then, ACP has becoming increasingly common internationally in the legal organization of the healthcare landscape and in healthcare itself. Initial legislation regarding the determination of patients' wishes in an advance directive, the appointment of a healthcare proxy, and/or other aspects of ACP now exist in various countries: e.g., Germany [7], Belgium [8], United Kingdom [9], Australia [10], Singapore [11], South Africa [12], South Korea [13], Argentina [14], Canada [15], New Zealand [16], Indonesia [17], Hong Kong [18], and Thailand [19]. Some countries, however, have no legal regulation in this area. Nonetheless, some of them, such as Norway [20] and Brazil [21], have issued

national recommendations.

Parallel to the (further) development of the ACP concept and the shaping of the legal landscape in recent decades, a large number of ACP interventions have been developed, tested in trials, and in some cases adopted as standard care (e.g. Respecting Choices® [22] or Let Me Decide [23]). As the number of studies increased, systematic reviews began to emerge that examined various aspects of ACP implementation. These reviews have investigated the effectiveness of ACP interventions in general or for specific target populations [e.g. 24–26], the healthcare providers' attitude toward and knowledge of ACP [e.g. 27–29], and facilitating and inhibiting factors for the implementation of ACP interventions ([e. g. 30, 31]).

Despite this growing body of research, however, to our knowledge there is no comprehensive review that systematically examines the target populations, settings, and theoretical foundations of ACP interventions that have been evaluated in studies. Such a review is needed to determine whether current ACP research aligns with the concept's foundational definition. Specifically, we examine whether ACP interventions reach individuals of all ages and health conditions and provide them with support in expressing their end-of-life care preferences. Of particular interest is whether ACP interventions have moved beyond targeting primarily ill or vulnerable populations to embrace the broader population-based approach envisioned in the original concept.

2.2.2 Aim

The aim of this scoping review is to provide a comprehensive mapping of ACP interventions that have been evaluated for their effectiveness or were under study until April 26, 2024, including their target groups and settings. This systematic overview will enable researchers and practitioners to identify patterns, gaps, and opportunities in current ACP implementation research. The main research question guiding this review is as follows:

What are the settings and target populations at patient level in which ACP interventions are implemented?

Additionally, the reviews seeks to answer the following secondary research questions:

What are the components of evaluated ACP interventions?

Was the development of intervention components guided by a theoretical approach, in particular a model, framework or theory?

Finally, the scoping review seeks to determine whether the research to date fulfils the

definition of ACP to enable all people regardless of age and health status to understand and communicate their wishes and preferences regarding medical and nursing at the end of life [2].

2.3 Methods

This scoping review was prepared using the Joanna Briggs Institute methodology for scoping reviews [32].

2.3.1 Search strategy

In March 2022, the databases MEDLINE via PubMed, PsycInfo via EBSCO, CINAHL via EBSCO and ScienceDirect were searched. The database search was updated in April 2024. The search algorithm was adapted to the specifications of each database. The following PubMed search algorithm was used as a basis:

(ACP[Title/Abstract] OR "advance care planning"[Title/Abstract] OR "Advance Care Planning" [Mesh] OR "anticipatory care planning"[Title/Abstract]) AND ("Clinical Studies as Topic"[Mesh] OR "Epidemiologic Studies"[Mesh] OR "Clinical Trial" [Publication Type] OR "clinical study" OR trial OR evaluation OR intervention OR "randomized controlled trial" OR "randomised controlled trial" OR RCT OR (study AND (cohort OR "case-control" OR comparative OR before-and-after OR pre-post OR longitudinal OR follow-up OR experimental OR "cluster-randomized" OR "cluster-randomised" OR observational OR "quasi-experimental")) OR "comparative experiment" OR "interrupted time series" OR "stepped-wedge" OR "hybrid effectiveness implementation" OR experiment)

Backward citation searching was not carried out due to the large number of studies already included.

2.3.2 Eligibility and exclusion criteria

Only studies written in English and German were included. Both quantitative and mixed-methods studies, were included, as well as study protocols with a before-and-after- (alternative: pre-post-) design, referring to measurements before and after the introduction or implementation of the intervention. The included literature must aim to evaluate at least the effectiveness of an ACP intervention at patient level. Studies that have only analyzed or planned to analyze implementation outcomes were excluded [33].

An intervention was considered to be an ACP intervention if the authors themselves described it as an ACP intervention, stated that it included parts of ACP, or associated it with

the concept of ACP. If ACP was found in the keywords chosen by the authors, the study was also included.

Studies that evaluated an intervention at healthcare provider level only and did not collect patient outcomes or had no intention of doing so were excluded, as this review intended to focus on the patient level. All types of reviews, meta-analyses and cross-sectional studies were excluded. Literature that did not report on a study (e.g. commentaries), abstracts and theses (with the exception of Ph.D. theses) were also excluded. Studies that evaluate a legal change were excluded as well.

2.3.3 Study selection

Study selection was a two-step process. In the first step, titles and abstracts were independently screened by two reviewers (JJ and NGD) using Rayyan [34]. Due to the large number of search results, we deviated from the Joanna Briggs Institute methodology for scoping reviews [32], which requires both reviewers to screen all of the search results. Instead, we based the screening process on the rapid review methodology [35]. JJ screened all titles and abstracts, while NGD screened 10% of them. Their results were then discussed. There were no conflicts between the two reviewers in 96.6% of the titles and abstracts screened by both. The remaining 3.4% ($n = 49$) were discussed and a consensus decision was reached. The second step was a full-text screening. Again, JJ screened all full texts, while NGD screened 14% of them. In 96.5% of the full texts screened by both, there was no conflict between the two reviewers. The remaining 3.5% ($n = 2$) were discussed and a consensus decision was reached [35]. If there had been disagreement between JJ and NGD during the two screening steps, the third member of the research group (JKN) would have been consulted in order to reach a majority decision. This was not necessary.

2.3.4 Data extraction and analysis

Data from studies that met the inclusion criteria were recorded in a standardized extraction file using MAXQDA 2022 and Microsoft Excel 365. Information was extracted on the authors, year of publication, country in which the study was conducted, target population of the intervention at patient level, setting of the intervention, intervention components (including delivery approaches, intervention intensity, and the theoretical basis of the intervention), and study type.

In order to make statements about the frequency of target groups, the patient inclusion and exclusion criteria of the included full texts were divided into the following subcategories: age, chronic/serious illness (including comorbidity and frailty) yes/no, disease, care recipient

yes/no, life expectancy, ACP status (e. g. ACP documents exist or not, health proxy was chosen or not), ethnicity and other group characteristics, language barriers, and cognitive impairment. The intervention components were categorized inductively by using a sample of the first data extract of 2022 ($n = 80$) and then applying the categorization to all included full texts (see Table 2-3 in section 2.4.5). The results of this scoping review are presented descriptively by reporting frequency.

2.3.5 Citation of included full texts

To ensure optimal readability of the results section, which encompasses 408 full texts, the studies included are not cited directly in the text. Instead, at the ends of sections 2.4.1 to 2.4.5, there are a references to the table in the appendix that lists the citations of the individual extraction elements. Additionally, the reference list in the appendix provides an alphabetical list of all the included full texts.

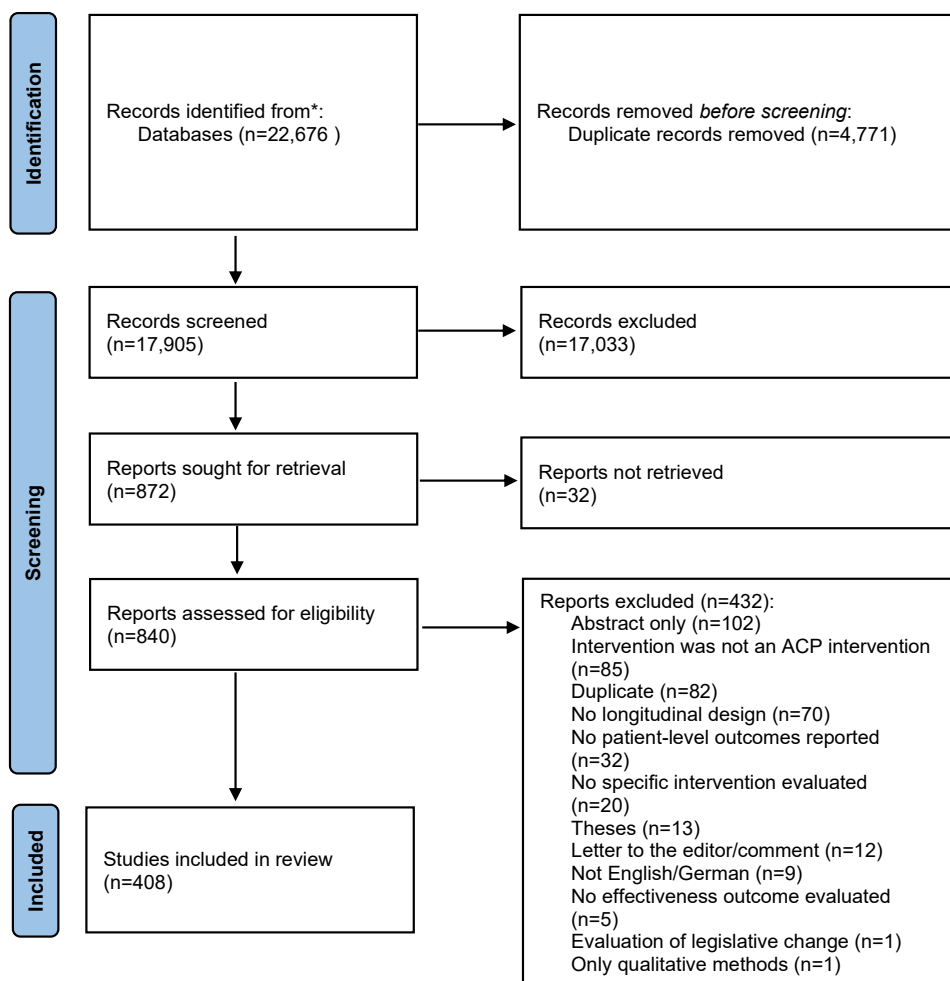
2.4 Results

2.4.1 Search results

The initial literature search in 2022 identified 18,429 records. The updated literature search in 2024 identified 4,247 additional records, resulting in a total of 22,676 records. After removing duplicates, 17,905 records were included in the title- and abstract screening. Of these, 872 were included in the full-text screening.

A total of 408 full-texts met the inclusion criteria and were used to answer the research questions. The remaining 464 full texts were excluded for various reasons, most commonly due to being abstracts only ($n=102$, 22.0%), not evaluating an ACP intervention ($n = 85$, 18.3%), or being multiple reports of the same intervention already included and/or duplicates ($n = 82$, 17.7%). Other exclusion reasons included non-longitudinal study design ($n = 70$, 15.1%), unavailable full texts despite extensive searches ($n = 32$, 6.9%), and lack of patient-level outcomes ($n = 32$, 6.9%). See Figure 2-1 for a complete list of exclusion reasons.

Figure 2-1: PRISMA flowchart for the scoping review adapted from [35]



2.4.2 Study characteristics

Most of the included studies were quantitative ($n = 316, 77.5\%$), while 92 studies (22.5%) used quantitative and qualitative methods. Among the studies with quantitative and qualitative methods, 39 (42.4%) described their approach as “mixed methods”, while the remainder combined quantitative and qualitative data collection without explicitly using this methodology.

Study designs comprised 172 (cluster) randomized controlled trials (42.2%), 31 nonrandomized controlled trials (7.6%), and 205 before-after-studies, cohort studies or other longitudinal study types (50.2%). Twenty-eight studies (6.9%) were characterized as quality improvement projects/studies, 56 as pilot studies (13.7%), and 20 as feasibility studies (4.9%). Fifty-five records (13.5%) were study protocols. See Appendix A1, Table 2-A1 for the citations.

2.4.3 Considered countries and care settings

The 408 included studies were conducted or planned across 30 countries, with nine studies involving multiple countries. Table 2-1 shows how studies were distributed across countries. Studies conducted in multiple countries were counted multiple times, bringing the total number of cases to 447. However, the geographic distribution was heavily skewed toward high-income countries. Of the 447 observed cases, the United States was considered in 246 cases (55.0%), followed by Australia and the United Kingdom ($n = 26$ each, 5.8%), Canada ($n = 22$, 4.9%), and Taiwan ($n = 14$, 3.1%). Notably, only two studies (0.4%) were conducted in upper-middle-income countries, and no studies were conducted in lower-rated countries, highlighting a significant geographic imbalance in ACP research.

Table 2-1: Number of studies by country

Country	Number (%) n=447	World Bank income groups 2024 [36]
Austria	1 (0.2)	High-income country
Australia	26 (5.8)	High-income country
Belgium	9 (2.0)	High-income country
Canada	22 (4.9)	High-income country
China	1 (0.2)	Upper-middle-income country
Czech Republic	3 (0.7)	High-income country
Denmark	6 (1.3)	High-income country
Estonia	1 (0.2)	High-income country
Finland	2 (0.4)	High-income country
France	3 (0.7)	High-income country
Germany	9 (2.0)	High-income country
Greece	1 (0.2)	High-income country
Hong Kong	9 (2.0)	High-income country
Italy	9 (2.0)	High-income country
Japan	6 (1.3)	High-income country
Mexico	1 (0.2)	Upper-middle-income country
New Zealand	1 (0.2)	High-income country
Norway	6 (1.3)	High-income country
Poland	1 (0.2)	High-income country
Republic of Ireland	6 (1.3)	High-income country
Singapore	3 (0.7)	High-income country
Slovenia	2 (0.4)	High-income country
South Korea	2 (0.4)	High-income country
Spain	1 (0.2)	High-income country
Sweden	1 (0.2)	High-income country
Switzerland	7 (1.6)	High-income country
Taiwan	14 (3.1)	High-income country
The Netherlands	22 (4.9)	High-income country
United Kingdom	26 (5.8)	High-income country
United States of America	246 (55.0)	High-income country

Regarding care settings, ACP interventions showed a bias toward institutional healthcare environments. More than half of all interventions were provided exclusively in hospital or clinic settings ($n = 215$, 52.7%), followed by nursing home or assisted living facilities ($n = 52$, 12.7%). In contrast, community-based approaches were markedly underrepresented:

only 36 studies (8.8%) were conducted exclusively in community settings, 31 (7.6%) in primary care practices, and 24 (5.9%) in home or home care settings. A small number of studies ($n = 22$, 5.4%) were conducted across multiple settings, while 28 (6.9%) took place in other specified settings. The ACP interventions reviewed are predominantly institution-focused rather than being integrated into everyday community life. See Appendix A1, Table 2-A2 for citations.

2.4.4 Target groups

Age-related targeting patterns

Analysis of age restrictions revealed limitations in the universal applicability of ACP interventions. Of the 408 studies, 256 (62.7%) contained explicit information on target age groups, with 42 different age restrictions/categories identified. The findings demonstrate a focus on older adults and a virtual exclusion of younger populations from ACP interventions. More than 90% of age-restricted studies ($n = 235$) targeted adults only with no upper age limit, while only 17 studies (6.6%) specified a maximum age. Most important for the universal vision of ACP, only 14 studies (5.5%) focused on children or young adults under 28 years, indicating that younger populations are almost entirely absent from current ACP research.

Of the 256 studies that contained explicit information on target age groups, 240 could be divided into distinct age categories. The most common age restrictions were 18+ years ($n = 108$, 45.0% of age-restricted studies) and 60+ years ($n = 73$, 30.4%) (see Table 2-2). This pattern suggests that ACP is predominantly conceptualized as relevant for older adults rather than as a life-course approach applicable to all ages as originally envisioned [2]. See Appendix A1, Table 2-A3 for citations.

Table 2-2: Frequency of age distribution of targeted populations

Age group	Frequency (%), $n = 240$
≤28	14 (5.8%)
16+	1 (0.4%)
18+	108 (45.0%)
30+	7 (2.9%)
45+	26 (10.8%)
60+	73 (30.4%)
75+	11 (4.6%)

Note: Studies are only counted if they provide specific age information and can be clearly classified into one of the categories.

Health status and illness-focused targeting

The analysis revealed a bias toward illness-focused ACP interventions, contradicting the concept's foundational principle of being relevant regardless of health status [2]. A

substantial majority of studies ($n = 265$, 65.0%) targeted only people with chronic or serious illnesses. Among the 204 studies (50%) that specified particular diseases or health conditions, cancer was by far the most common focus, with 84 studies (41.2%) including only cancer patients and an additional 19 studies (9.3%) including cancer patients alongside other conditions. Heart disease was the second most targeted condition, featured in 36 studies either exclusively ($n = 19$, 9.3%) or in combination with other conditions ($n=17$, 8.3%).

In contrast, only 92 studies (22.6% of the 408 studies) targeted individuals who were neither chronically/seriously ill nor in need of care, representing healthy populations. This finding is particularly meaningful, as it suggests that ACP interventions have evolved to focus primarily on palliative or end-of-life care rather than serve as a universal healthcare planning tool for all individuals regardless of their health status. See Appendix A1, Table 2-A4 for citations.

Care dependency

Ninety-two of the 408 studies (22.5%) exclusively included people requiring care assistance. Two thirds of these studies ($n = 59$, 64.1%) focused on nursing home or assisted-living residents, while 17 (18.5%) included community-dwelling individuals requiring care, and 11 (12.0%) involved formal or informal home care recipients. In five studies (1.2%), people in need of care were part of the target group. See Appendix A1, Table 2-A5 for citations.

Life expectancy as an exclusion mechanism

The use of life expectancy criteria further reinforces the illness-focused nature of current ACP interventions. Sixty-nine studies (16.9%) used life expectancy as an inclusion or exclusion criterion. Among these, 40 studies (58.0%) included only patients with a life expectancy of 12 months or less, while seven (10.1%) extended this to 24 months. The frequent use of “surprise questions”¹ (used in 26 studies, 37.7% of those with life expectancy criteria) and short-term survival expectations demonstrates that many ACP interventions are designed primarily for end-of-life rather than ACP. See Appendix A1, Table 2-A6 for citations.

Advance care planning status

A limitation regarding the ACP status of patients for inclusion or exclusion was reported in 48 studies (11.8%). In 31 of the 48 (64.6%) studies, the requirement for participation was that no current ACP documents existed and no health proxy was available prior to participation. Thirteen studies (27.1%) indicated the necessity of a health care proxy and one

¹ Would the healthcare provider be surprised if a patient were to die within a certain timeframe?

study (2.3%) required the existence of a health proxy but without an advance directive. In one study (2.1%), an advance directive was required for participation. In another (2.1%), patients had to be engaged in ACP, and in a third (2.1%), prior participation in an ACP study was an exclusion criterion. See Appendix A1, Table 2-A7 for citations.

Limited diversity and accessibility

The research also revealed limitations in terms of population diversity and accessibility. Only 31 studies (7.6%) specifically addressed ethnicity in their inclusion criteria, with nine studies (29.0%) focusing exclusively on African Americans, eight (25.8%) on Latino populations, one each (3.2%) on Chinese American and Korean American participants, and three studies (9.7%) on aboriginal participants. Four studies (12.9%) included only undefined underrepresented groups or were sensitive to racial and ethnic minorities, one study (3.2%) oversampled African Americans and Latinos purposefully, and another (3.2%) included two participating sites primarily serving African American and Latino populations. This limited attention to ethnic diversity is particularly problematic, given known disparities in healthcare access and end-of-life care across different ethnic groups.

Seventeen of the 408 studies (4.2%) reported additional group characteristics in their inclusion criteria. Five of these 17 studies (29.4%) included only veterans, two (4.2%) included only students, and two (11.8%) included only women. One study (5.9%) focused exclusively on older, single people, one (5.9%) focused exclusively on homeless and low-income people, and another (5.9%) focused only on homeless people. One study (5.9%) each focused only on Medicare beneficiaries, who would benefit from an advance directive, people at high risk of hospitalization, frequent hospital attenders, and for members of an employer-union health fund.

One-hundred and eighty-four studies (45.1%) reported exclusion criteria related to language barriers or cognitive abilities. Of these, 154 studies (83.7%) excluded patients due to language barriers, with only four studies (2.2%) providing translation support. Similarly, 95 studies (51.6%) excluded patients with cognitive impairments. Only one of the 185 studies (0.5%) reported that patients were allowed to be supported by a care giver and only one study (0.5%) excluded patients without cognitive impairment specifically. These exclusion practices prevent large segments of the population from accessing ACP interventions, contradicting the principle of universal applicability. See Appendix A1, Table 2-A8 for citations.

2.4.5 Delivery approaches and intervention components

A total of 416 interventions were extracted. This number reflects the fact that some studies reported more than one intervention. Forty-one (9.9%) of the interventions were for care providers only but the respective studies reported patient outcomes. Little or no information was published about how these 41 interventions were delivered. At the time of publication, one study (0.2%) reported that the intervention had not yet been developed. See Appendix A1, Table 2-A9 for citations.

Delivery approach and intervention intensity

Most interventions ($n = 353$, 84.9%) were delivered individually rather than in group settings. Thirty-five studies (8.4%) reported that the intervention was (partly) provided in a group setting and 181 interventions (43.2%) included family members or other close people. Regarding intervention intensity, 111 interventions (26.7%) reported only a single session, while 157 (37.7%) involved multiple sessions. Notably, for 148 interventions (35.6%), the frequency of delivery could not be determined from the published information, indicating potential issues with intervention reporting quality. Three of these 148 (2.0%) studies reported that the intervention provider was available on demand or 24/7. A total of eight interventions (1.9%) reported on demand or 24/7 availability. See Appendix A1, Table 2-A10 for citations.

Intervention components

Table 2-3 shows how often the different intervention components were described in the studies. The most common intervention components were individual conversations or interviews ($n = 238$, 57.2%) and training for intervention providers ($n = 226$, 54.1%). Traditional educational materials dominated the delivery methods, with written information being the third most common component ($n = 96$, 23.1%). Modern, interactive approaches were less common: online or computerized interventions appeared in only 41 studies (9.9%), and innovative methods such as games ($n = 12$, 2.9%) or mobile applications ($n = 8$, 1.9%) were rare. This pattern suggests that ACP interventions have not yet fully embraced digital technologies that could facilitate broader population reach.

A theoretical foundation for an intervention was reported for 81 interventions (19.5%), indicating either a lack of reporting on the development of the interventions, or a lack of theoretical foundation for the interventions, which could negatively affect the interventions' effectiveness. See Appendix A1, Table 2-A11 for citations.

Table 2-3: Intervention components and their frequencies

Intervention component	<i>n</i> = 416 (%)
Conversation/interview	238 (57.2)
Training/coaching for intervention providers	226 (54.1)
Written information, e.g., brochures, flyers, patient letters, wallet cards for patients	96 (23.1)
Theoretical foundation of the intervention	81 (19.5)
Video	56 (13.5)
Online media, computerized tool, website	41 (9.9)
Workbook (written processing of materials)	36 (8.7)
Lecture/presentation/webinar	21 (5.0)
(Video) case vignettes, hypothetical scenarios	16 (3.8)
Game (board game, card game, computer game)	12 (2.9)
Unspecified tool for care provider without information for delivery to the patient	11 (2.6)
Workshop	9 (2.2)
App/patient portal	8 (1.9)
Interactive tasks, role play	5 (1.2)
Written information for relatives or other close people	3 (0.7)
Case conference incl. relatives or other close people	3 (0.7)
Simulation of a conversation	3 (0.7)
Community trip	1 (0.2)
Quiz	1 (0.2)
Values inventory	1 (0.2)
Card for location of ACP documents	1 (0.2)
Meditation	1 (0.2)
Cartoon	1 (0.2)
To-do list	1 (0.2)
Lunch	1 (0.2)

Note: ACP = Advance care planning.

2.5 Discussion

This scoping review examines whether current ACP research aligns with the concept's foundational definition of enabling all people, regardless of age and health status, to express their wishes and preferences for medical and nursing care [2]. Our results reveal that current ACP research diverges notably from the concept's foundational vision of universal applicability. Instead of serving all individuals regardless of age and health status, ACP interventions predominantly target older adults with serious illnesses in institutional healthcare settings. This pattern suggests an evolution toward palliative care rather than proactive healthcare planning for all populations, raising important questions about whether current implementation approaches align with ACP's original conceptual framework.

2.5.1 Target population bias: From universal access to selective intervention

The most striking finding of this review is the systematic exclusion of healthy and younger populations from ACP interventions. Of the interventions described in the studies, 65.0% focus exclusively on chronically or seriously ill patients, while only 22.6% targeted individuals who were neither chronically ill nor in need of care. This pattern represents a fundamental shift away from ACP's original conceptualization as a universal life skill toward a medicalized intervention primarily reserved for those approaching end of life.

The age distribution further reinforces this concerning trend. One third of all age-categorized studies exclusively target older people (aged 60 or over). Most troubling is the virtual absence of children and young adults from ACP research, with only 14 studies (5.8%) focusing on individuals under 28 years. This age bias contradicts growing evidence that younger populations also benefit from ACP [38, 39] and suggests that we are missing critical opportunities for early engagement with healthcare decision-making processes.

The rationale for targeting vulnerable populations is understandable from a clinical risk perspective: seriously ill and elderly individuals face a greater likelihood of critical care situations [40] requiring ACP. However, this narrow focus overlooks several compelling arguments for broader population engagement. First, unintentional injuries represent the leading cause of death among young adults, creating scenarios where ACP becomes critically important despite apparent good health [41]. Second, early engagement with ACP facilitates ongoing reflection and communication about healthcare preferences as individuals progress through life stages and experience changing health circumstances [42]. Third, younger adults frequently assume caregiver roles for family members, positioning them as crucial facilitators of ACP discussions with older relatives [42]. By excluding younger,

healthier populations, current ACP interventions miss opportunities to develop these essential skills before they become urgently needed.

2.5.2 Geographic concentration and cultural limitations

Our analysis reveals a pronounced geographic concentration of ACP research, with 60.3% of interventions originating from the United States. This concentration raises important questions about the cultural transferability and global applicability of current ACP approaches. While the historical development of ACP in the United States during the 1960s [4] partially explains this dominance, the limited international diversification suggests that ACP research has not adequately addressed cross-cultural variations in healthcare decision-making, family dynamics, and end-of-life preferences.

The absence of robust ACP research in many countries, particularly nations that are not classified as high-income countries [37], represents a significant gap that limits our understanding of how ACP concepts might be adapted to different healthcare systems, cultural contexts, and resource settings. This geographic bias may perpetuate approaches that are not universally applicable and could impede the global adoption of ACP as a standard healthcare practice.

2.5.3 Setting bias: Institutionalization versus community integration

The predominance of hospital and clinic settings (52.7%) and nursing home facilities/assisted-living settings (12.7%) in ACP intervention delivery reveals another fundamental departure from the concept's universal vision. This institutional focus limits access for individuals who are not already engaged with healthcare systems. In contrast, community-based approaches remain markedly underrepresented, with only 8.8% of studies conducted exclusively in community settings.

This setting bias has profound implications for population-wide ACP implementation. If ACP is to become a universal competency – skill that all individuals develop as part of their life planning alongside financial planning and career development – it must be accessible outside traditional healthcare environments. The current institutional focus suggests that ACP interventions are reactive rather than proactive, reaching individuals only after they have entered healthcare systems due to illness or age-related decline.

A truly universal ACP approach would require integration into community settings such as schools, workplaces, religious organizations, and civic institutions. This would position ACP as a normal part of adult development rather than a medical intervention reserved for the

vulnerable or terminally ill.

2.5.4 Accessibility barriers and equity concerns

Perhaps most concerning for the goal of universal ACP access are the systematic exclusion practices documented in this review. Nearly half of all studies (45.1%) reported eligibility criteria related to language barriers or cognitive abilities, with 83.7% of these studies excluding patients due to insufficient language skills and only 2.2% providing translation support. Similarly, 51.6% of these studies reported exclusion criteria for patients with cognitive impairments.

These exclusion practices directly contradict the principle of universal applicability and create significant equity concerns. Language barriers and cognitive limitations are precisely the circumstances where ACP becomes most crucial, yet current research systematically excludes these populations. This approach not only limits the evidence base for vulnerable populations, but also perpetuates healthcare disparities by denying access to interventions that could improve care quality and decision-making processes.

2.5.5 The imperative for population-wide advance care planning competency

The findings of this review support a reconceptualization of ACP from a targeted institutionalized intervention to a universal societal competency. Just as financial literacy and civic engagement are considered essential life skills that all citizens should develop regardless of their current economic status or political involvement, ACP should be positioned as a core competency for navigating modern healthcare systems and life transitions.

This shift requires moving beyond the current paradigm that views ACP as relevant primarily for the sick and elderly toward an approach that recognizes healthcare decision-making as a lifelong process relevant to all individuals. Such a transformation would involve several key changes: integrating ACP education into standard curricula at various life stages; developing community-based programs that reach beyond traditional healthcare settings; creating culturally adapted approaches that respect diverse values and decision-making processes; and ensuring accessibility for individuals with language barriers, cognitive limitations, and other potential obstacles to participation.

2.5.6 Intervention development and theoretical foundations

The limited use of theoretical frameworks in ACP intervention development (only 19.5% of studies reported theoretical foundations) represents a gap that may explain some of the

implementation difficulties identified in this review. Theory-driven interventions are typically more effective and generalizable because they are based on established understanding of behavior change mechanisms and implementation processes. The absence of robust theoretical grounding suggests that many ACP interventions may be developed without sufficient consideration of factors that influence individual engagement, healthcare system integration, or long-term sustainability [43].

This theoretical deficit is particularly problematic for population-wide implementation, which requires understanding of diverse motivational factors, cultural influences, and system-level barriers that affect different population segments. Additionally, the finding that only 54.1% of interventions report training for providers suggests inconsistent implementation quality, which could undermine intervention effectiveness and contribute to variable outcomes across studies.

2.5.7 Implications for policy and practice

These findings have significant implications for healthcare policy and ACP implementation strategies. Current approaches that focus primarily on high-risk populations may be missing opportunities for earlier engagement that could improve long-term healthcare planning and decision-making quality. Policymakers should consider initiatives that promote ACP as a standard component of adult education and civic engagement rather than limiting it to medical contexts.

Moreover, healthcare systems should develop strategies for community integration that extend beyond traditional clinical settings. This might include partnerships with educational institutions, employers, community organizations, and digital platforms that can reach diverse populations during routine life activities rather than during health crises.

2.5.8 Limitations

This scoping review analyzed 408 studies, which required categorization and summarization to maintain manageable scope for the research team. Only information reported in included full texts was analyzed, and due to the large number of studies, we did not seek additional information from related publications. This approach may result in some information loss but was necessary for comprehensive coverage of the literature.

Additionally, this review did not assess study quality or weight studies based on sample size or intervention effectiveness, as is typical for scoping reviews. While this approach provides a comprehensive overview of the field, it does not distinguish between high-quality evidence

and preliminary findings. The review was also limited to English and German language publications, which may have contributed to the observed geographic bias in findings.

2.5.9 Conclusion

This scoping review demonstrates that current ACP research diverges notably from the concept's foundational vision of universal applicability. Instead of serving as a proactive healthcare planning tool for all individuals regardless of age and health status, ACP interventions have evolved into a primarily reactive, illness-focused approach that serves predominantly older and chronically ill populations in institutional settings.

The evidence supports a call for reconceptualization of ACP implementation. Rather than continuing to develop interventions that reach individuals only after they become ill or elderly, the field should prioritize population-wide approaches that position ACP as an essential life competency. This transformation requires moving beyond institutionalized models toward community-integrated, culturally responsive, and universally accessible approaches that truly fulfill ACP's original aim of empowering all individuals to participate in their healthcare decision-making processes.

Achieving this vision will require coordinated efforts across multiple sectors, including healthcare systems, educational institutions, community organizations, and policymakers. Only through such comprehensive approaches can ACP evolve from its current status as a specialized institutionalized intervention to become the universal societal competency that its foundational definition envisioned.

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Appendix

A1: Citations

Table 2-A1: Citation of section 2.4.2: Study Characteristics

Citation element	Citation
Quantitative methods	[1, 3, 4, 6, 8–19, 21–25, 27–34, 37–43, 46–50, 52, 54, 56, 58–67, 69–74, 76–78, 80, 82–86, 89–92, 94, 95, 97–104, 106–108, 110–113, 115–118, 121–124, 126, 127, 129–132, 134–140, 142–152, 155–161, 163–168, 170–173, 175, 176, 178–191, 194–196, 198, 199, 201–206, 209–212, 214, 217, 218, 220–224, 226–229, 231–233, 237–240, 242–251, 253, 255, 256, 259–262, 267, 268, 271–277, 279–284, 286–292, 294, 296–300, 302–312, 314–316, 318, 321, 323–328, 330–334, 336, 338–340, 342, 343, 345–351, 354–359, 361–364, 366, 368, 369, 371–375, 377–379, 385–395, 397–399, 401, 402, 404–408]
Quantitative and qualitative methods	[2, 5, 7, 20, 26, 35, 36, 44, 45, 51, 53, 55, 57, 68, 75, 79, 81, 87, 88, 93, 96, 105, 109, 114, 119, 120, 125, 128, 133, 141, 153, 154, 162, 169, 174, 177, 192, 193, 197, 200, 207, 208, 213, 215, 216, 219, 225, 230, 234–236, 241, 252, 254, 257, 258, 263–266, 269, 270, 278, 285, 293, 295, 301, 313, 317, 319, 320, 322, 329, 335, 337, 341, 344, 352, 353, 360, 365, 367, 370, 376, 380–384, 396, 400, 403]
Mixed methods	[20, 35, 36, 51, 76, 87, 93, 120, 125, 128, 153, 154, 162, 197, 207, 208, 213, 215, 230, 236, 257, 265, 266, 269, 278, 285, 293, 319, 320, 322, 335, 352, 353, 360, 367, 381–384]
(Cluster) randomized controlled trials	[1, 2, 4, 9, 10, 14, 15, 18, 21, 23, 25, 28, 30, 38–40, 42–45, 47, 50, 51, 60, 64, 68, 74–76, 86–89, 92, 94, 97–99, 101–103, 105–110, 112, 114, 116, 120–124, 130, 132, 135, 136, 141, 144, 145, 148, 153, 154, 159, 162, 163, 166, 167, 170, 171, 174, 177, 181–183, 185–188, 190, 191, 193, 195, 200, 207, 209–212, 214, 218, 220–223, 225, 228, 233–235, 237–240, 242, 250, 251, 254, 256, 257, 261, 264, 272–275, 277, 281, 284, 289–291, 294, 296, 297, 301–303, 308, 311, 312, 315, 320–323, 328, 330–336, 338, 339, 341, 344–347, 349, 357, 358, 360–363, 366, 369–371, 378, 382, 388, 391, 394, 395, 399, 405]
Nonrandomized controlled trials	[5, 7, 13, 33, 46, 52, 56, 58, 62, 77, 78, 83, 91, 117, 125, 129, 164, 176, 192, 194, 244, 255, 258, 298, 309, 319, 351, 356, 392, 397, 403]
Before-after-studies, cohort studies or other longitudinal study types	[3, 6, 8, 11, 12, 16, 17, 19, 20, 22, 24, 26, 27, 29, 31, 32, 34–37, 41, 48, 49, 53–55, 57, 59, 61, 63, 65–67, 69–73, 79–82, 84, 85, 90, 93, 95, 96, 100, 104, 111, 113, 115, 118, 119, 126–128, 131, 133, 134, 137–140, 142, 143, 146, 147, 149–152, 155–158, 160, 161, 165, 168, 169, 172, 173, 175, 178–180, 184, 189, 196–199, 201–206, 208, 213, 215–217, 219, 224, 226, 227, 229–232, 236, 241, 243, 245–249, 252, 253, 259, 260, 262, 263, 265–271, 276, 278–280, 282, 283, 285–288, 292, 293, 295, 299, 300, 304–307, 310, 313, 314, 316–318, 324–327, 329, 337, 340, 342, 343, 348, 350, 352–355, 359, 364, 365, 367, 368, 372–377, 379–381, 383–387, 389, 390, 393, 396, 399–402, 404, 406–408]
Quality improvement projects/studies	[6, 29, 31, 32, 55, 66, 70, 73, 78, 104, 127, 155, 163, 194, 203, 206, 230, 255, 259, 264, 269, 271, 299, 304, 337, 342, 343, 397]
Pilot studies	[4, 8, 16, 20, 34, 35, 37, 41, 49, 53, 65, 67, 69, 87, 105, 119, 137, 142, 153, 165, 174, 182, 184, 185, 205, 217, 220, 226, 227, 234, 246, 253, 269–271, 278, 284, 291, 305, 307, 308, 314, 317, 327, 330, 332, 341, 348, 369, 370, 376, 379, 385, 386, 398, 400]
Feasibility studies	[44, 51, 68, 80, 111, 113, 118, 119, 136, 208, 236, 241, 263, 266, 300, 302, 326, 365, 401, 403]
Study protocols	[2, 7, 9, 23, 50, 75, 79, 93, 94, 100, 101, 107, 119–121, 128, 135, 145, 162, 177, 183, 186, 193, 200, 204, 207, 211, 225, 230, 233, 239, 254, 256, 266, 272, 281, 290, 294, 295, 297, 303, 315, 320, 322, 326, 334, 341, 344, 346, 349, 360, 366, 378, 395, 399]

Table 2-A2: Citation of section 2.4.3: Considered countries and care settings

Citation element	Citation
Australia	[2, 47, 52, 62, 67, 85, 86, 130, 131, 164, 166, 168, 178, 203, 214, 228, 232, 236, 237, 243, 285, 290, 313, 317, 323, 337]
Austria	[233]
Belgium	[5, 87, 93, 187, 188, 344, 345, 371, 378]
Canada	[22, 43, 45, 71, 89, 116, 118, 128, 140, 145–148, 160, 179, 248, 278, 352, 353, 386, 387, 404]
China	[83]
Czech Republic	[22, 45, 128]
Denmark	[28, 50, 187, 188, 328, 367]
England*	[19, 81, 167, 216, 302, 395]
Estonia	[233]
Finland	[195, 371]
France	[42, 84, 360]
Germany	[23, 120, 141, 185, 233, 309, 315, 322, 370]
Greece	[233]
Hong Kong	[56–60, 157, 200, 215, 403]
Italy	[22, 45, 119, 128, 187, 188, 233, 266, 371]
Japan	[182, 254, 258, 319, 356, 401]
Mexico	[339]
New Zealand	[305]
Norway	[1, 90, 91, 207, 297, 301]
Poland	[371]
Republic of Ireland	[22, 44, 45, 68, 128, 260]
Singapore	[139, 177, 225]
Slovenia	[187, 188]
South Korea	[171, 405]
Spain	[303]
Sweden	[233]
Switzerland	[41, 125, 162, 191, 310, 350, 371]
Taiwan	[61, 64, 149–152, 175, 176, 204, 208, 209, 351, 358, 402]
The Netherlands	[22, 45, 49, 69, 92, 113, 128, 144, 186–188, 217, 261, 326, 362, 371–377]
United Kingdom	[13, 16, 19, 22, 44, 45, 51, 55, 68, 80, 81, 96, 128, 129, 167, 187, 188, 199, 216, 233, 241, 257, 302, 342, 371, 395]
United States of America	[3, 4, 6–12, 14, 15, 17, 18, 20, 21, 24–27, 29–40, 46, 48, 53, 54, 63, 65, 66, 70, 72–79, 82, 88, 94, 95, 97–112, 114, 115, 117, 121–124, 126, 127, 132–138, 142, 143, 153–156, 158, 159, 161, 163, 165, 169, 170, 172–174, 180, 181, 183, 184, 189, 192–194, 196–198, 201, 202, 205, 206, 210–213, 218–224, 226, 227, 229–231, 234, 235, 238–240, 242, 244–247, 249–253, 255, 256, 259, 262–265, 267–277, 279–284, 286–289, 291–296, 298–300, 304, 306–308, 311, 312, 314, 316, 318, 320, 321, 324, 325, 327, 329–336, 338, 340, 341, 343, 346–349, 354, 355, 357, 359, 361, 363–366, 368, 369, 379–385, 388–394, 396–400, 406–408]
Hospital or clinic setting	[3, 6, 8, 10, 12, 14, 15, 17, 18, 23, 24, 28, 30, 32, 34–36, 42, 47–50, 52, 54, 55, 59–61, 65–67, 69, 70, 72–78, 81, 82, 84, 86, 89, 92, 95, 98, 99, 102, 103, 105–107, 111, 113, 117, 118, 121–124, 126, 132, 136, 142, 143, 150–152, 155, 156, 161, 163, 165–167, 172, 173, 175–178, 181, 183, 185, 187–189, 191–194, 196, 198–201, 203, 205, 206, 208–212, 217, 219, 220, 222–226, 229, 232–237, 239, 240, 243, 247–249, 251, 252, 254–258, 263, 264, 266, 267, 269–271, 273–276, 279, 280, 289–291, 296, 297, 299, 300, 302, 303, 306–308, 310, 311, 313, 314, 316, 317, 319–322, 324–326, 328, 330–332, 334–337, 339, 341, 342, 347, 349, 350, 354, 356, 358, 361, 363, 364, 368, 369, 372, 377–379, 385, 387, 388, 390–392, 394–399, 401, 402, 405, 406, 408]
Nursing home or assisted living setting	[1, 2, 5, 13, 19, 22, 31, 45, 56, 58, 62, 83, 88, 116, 119, 120, 125, 127, 128, 130, 134, 135, 139, 157, 159, 169, 170, 179, 184, 195, 202, 207, 214, 216, 218, 228, 238, 241, 242, 244, 246, 260, 261, 265, 285, 301, 309, 348, 351, 352, 357, 371]
Community setting	[4, 7, 20, 27, 38, 53, 64, 115, 131, 137, 138, 149, 153, 154, 171, 180, 182, 197, 215, 227, 245, 250, 253, 268, 272, 277, 283, 327, 340, 355, 380–384, 403]

Primary care practice setting	[9, 11, 16, 25, 37, 39, 40, 44, 63, 68, 87, 94, 97, 101, 104, 112, 114, 133, 145, 174, 262, 294, 298, 304, 344, 345, 362, 366, 374, 393, 400]
Home or home care setting	[29, 57, 71, 79, 85, 90, 91, 93, 141, 144, 162, 168, 190, 204, 213, 231, 278, 284, 286, 353, 359, 365, 376, 386]
Multiple settings	[41, 46, 80, 107, 110, 146–148, 164, 186, 221, 281, 305, 312, 315, 323, 329, 367, 373, 375, 389, 404]
Other specified settings	[21, 33, 43, 51, 96, 100, 109, 110, 129, 140, 158, 160, 230, 259, 282, 287, 288, 292, 293, 295, 318, 333, 338, 343, 346, 360, 370, 407]

Table 2-A3: Citation of section 2.4.4: Target groups – Age-related targeting patterns

Citation element	Citation
Explicit information on target age groups	[1, 3, 4, 7–11, 17, 18, 24, 27, 30, 33, 34, 39, 40, 43, 44, 46–51, 54, 57–60, 64, 68, 72, 73, 75, 77, 80, 82, 83, 86, 87, 89, 91, 92, 94, 95, 97–103, 106, 108–110, 112–115, 117, 118, 123, 124, 130–133, 136, 137, 141, 145–156, 158–162, 164, 166, 167, 171–177, 180, 182–186, 188–191, 193, 194, 197, 200, 201, 204, 207–209, 213, 215, 218–220, 223–227, 234, 236, 238–243, 248–250, 253, 254, 257, 258, 261–264, 272, 273, 276, 277, 280, 281, 283, 284, 289–292, 294, 297, 299–302, 305, 308, 310, 312, 314–316, 318–320, 323, 326–328, 331, 332, 334, 336–339, 341, 345–349, 355–357, 359, 360, 363–368, 370, 373–377, 379, 380, 382, 384–387, 389–392, 394, 395, 397–399, 401–406, 408]
Adults only with no upper age limit	[1, 3, 4, 7–11, 17, 18, 24, 27, 30, 33, 34, 39, 40, 43, 44, 46–51, 54, 57–60, 64, 68, 72, 73, 75, 77, 80, 82, 83, 86, 87, 89, 91, 92, 94, 95, 97–103, 106, 108–110, 112–115, 117, 118, 123, 124, 130–133, 136, 137, 141, 145–156, 158–162, 164, 166, 167, 171–177, 180, 182–186, 188–191, 193, 194, 197, 200, 201, 204, 207–209, 213, 215, 218–220, 223–227, 234, 236, 238–243, 248–250, 253, 254, 257, 258, 261–264, 272, 273, 276, 277, 280, 281, 283, 284, 289–292, 294, 297, 299–302, 305, 308, 310, 312, 314–316, 318–320, 323, 326–328, 331, 332, 334, 336–339, 341, 345–349, 355–357, 359, 360, 363–368, 370, 373–377, 379, 380, 382, 384–387, 389–392, 394, 395, 397–399, 401–406, 408]
Maximum age	[15, 20, 26, 76, 105, 107, 111, 210, 221, 222, 245, 251, 256, 330, 361, 378, 396]
Children or young adults under 28	[15, 20, 74, 79, 111, 205, 217, 221, 222, 245, 251, 256, 361, 378]
≤28	[15, 20, 74, 79, 111, 205, 217, 221, 222, 245, 251, 256, 361, 378]
16+	[140]
18+	[7, 8, 10, 11, 20, 26, 30, 34, 50, 51, 54, 57, 59, 60, 73, 77, 82, 87, 89, 91, 92, 95, 100, 102, 103, 105–108, 110, 117, 123, 131, 132, 136, 137, 149, 151, 155, 156, 158, 160, 162, 164, 166, 167, 171, 177, 185, 191, 197, 201, 208, 223, 225, 236, 243, 245, 248, 254, 264, 272, 273, 276, 280, 283, 289–292, 294, 308, 310, 314–316, 318, 320, 323, 326–328, 330, 332, 334, 336–339, 345, 356, 360, 366, 367, 370, 376, 380, 382, 384, 385, 389, 394, 396, 397, 401, 402, 405, 408]
30+	[118, 183, 227, 277, 364, 379, 390]
45+	[18, 39, 40, 112, 150, 152–154, 174, 189, 204, 234, 250, 253, 262, 281, 299, 300, 331, 347, 349, 357, 359, 395, 403, 406]
60+	[1, 3, 4, 17, 24, 27, 33, 43, 44, 48, 58, 68, 72, 80, 83, 94, 98, 99, 101, 109, 114–116, 124, 130, 133, 141, 145, 148, 159, 161, 175, 176, 182, 184, 190, 193, 200, 207, 209, 213, 215, 218–220, 224, 238, 240–242, 249, 257, 258, 260, 263, 284, 297, 301, 302, 319, 341, 346, 348, 351, 355, 363, 365, 368, 386, 387, 391, 392, 398]
75+	[47, 49, 86, 172, 186, 194, 261, 373–375, 399]

Table 2-A4: Citation of section 2.4.4: Target groups – Health status and illness-focused targeting

Citation element	Citation
Only people with chronic or serious illnesses	[1–4, 6, 8–10, 12, 14, 15, 17, 21–23, 25, 26, 28, 30, 32, 34–38, 41, 42, 44–46, 49–52, 55, 57–59, 62, 63, 65, 67–69, 71, 74–80, 82–85, 87–93, 95–108, 110, 111, 113, 114, 116–118, 121–123, 126, 128, 129, 132, 133, 135, 140, 142–144, 146, 150–152, 155, 156, 159, 160, 162–170, 172, 174, 177, 178, 181–183, 185, 187–189, 192, 193, 195–198, 200, 201, 205, 207, 208, 210–213, 215–217, 221–223, 225, 226, 229, 232–238, 241–243, 250, 251, 253–259, 261, 263–267, 269–274, 278, 280, 282, 284, 286–291, 293–296, 300, 302, 303, 306–308, 311, 314–323, 325, 326, 328, 330, 332–337, 339, 341–344, 349, 350, 353–362, 364–366, 369, 370, 372, 376, 378, 379, 381, 385, 386, 388, 389, 393–397, 399–401, 403, 405–408]
Disease or health condition specified	[1–3, 5, 6, 8–10, 14, 15, 17, 21–23, 25, 28, 30, 32, 34–36, 38, 41, 42, 45, 46, 49–51, 54, 55, 65, 67, 69, 73–80, 82, 84, 88–93, 95, 97, 99–105, 108, 111, 113, 117, 118, 121, 122, 126, 128, 129, 132, 135, 140, 143, 144, 146, 147, 150–152, 155, 156, 159, 160, 162, 164–167, 169, 174, 177, 178, 181, 183, 185, 187, 188, 193, 197, 201, 208, 210–213, 216, 221–223, 225, 226, 229, 232–238, 241, 247, 251, 254–259, 264–267, 269–274, 280, 282, 284, 287–289, 291, 293–296, 300, 302, 303, 306–308, 311, 314–316, 318, 320–323, 325, 326, 328, 330–336, 339, 341, 343, 350, 353, 354, 356–358, 360–362, 369, 370, 372, 378, 379, 385, 386, 388, 393, 395, 397, 399–403, 405, 407, 408]
Only cancer patients	[8–10, 15, 25, 30, 35, 42, 46, 49–51, 67, 74, 77, 78, 82, 84, 90, 91, 102–105, 108, 111, 117, 122, 126, 151, 155, 156, 160, 165–167, 177, 185, 187, 188, 193, 197, 208, 221, 236, 237, 251, 254–256, 259, 264, 267, 272–274, 282, 287, 289, 291, 293, 294, 296, 307, 311, 315, 318, 320, 322, 330, 339, 343, 354, 358, 360, 361, 370, 372, 378, 388, 393, 400, 405, 408]
Including cancer patients alongside other conditions	[3, 6, 28, 34, 75, 89, 97, 113, 132, 144, 146, 147, 234, 258, 284, 314, 328, 357, 362]
Heart disease only	[17, 23, 32, 69, 99, 164, 174, 225, 229, 280, 300, 303, 306, 321, 331, 356, 379, 395, 397]
Heart disease in combination with other conditions	[3, 6, 28, 34, 75, 95, 97, 121, 159, 181, 234, 258, 265, 284, 326, 328, 362]
Individuals neither chronically/serious ill nor in need of care	[7, 11, 16, 18, 20, 24, 27, 33, 39, 40, 47, 48, 54, 61, 66, 73, 81, 86, 94, 109, 112, 124, 131, 136, 138, 141, 145, 148, 149, 153, 158, 161, 171, 173, 175, 176, 180, 184, 190, 191, 194, 199, 203, 206, 209, 219, 220, 224, 227, 228, 230, 231, 239, 240, 245, 247–249, 252, 262, 268, 275–277, 279, 292, 298, 299, 310, 313, 324, 327, 329, 331, 338, 345–347, 363, 368, 374, 377, 380, 382–384, 387, 390–392, 398, 402]

Table 2-A5: Citation of section 2.4.4: Target groups – Care dependency

Citation element	Citation
Only people requiring care assistance	[1, 2, 4, 5, 13, 19, 21, 22, 29, 31, 38, 41, 43, 45, 46, 52, 53, 56–60, 62, 64, 68, 80, 83, 85, 88, 97, 115, 116, 118–120, 125, 127, 128, 130, 132, 134, 135, 137, 139–142, 154, 157, 159, 162, 169, 170, 179, 184, 186, 195, 202, 204, 207, 213–216, 218, 228, 231, 238, 241, 242, 244, 246, 253, 260, 261, 265, 285, 286, 301, 305, 309, 323, 340, 348, 351, 352, 357, 359, 366, 371, 373, 386]
Nursing home or assisted living residents	[1, 2, 4, 5, 13, 19, 22, 31, 41, 45, 52, 56, 58, 59, 62, 83, 88, 116, 119, 120, 125, 127, 128, 130, 132, 134, 135, 139, 157, 159, 162, 169, 170, 179, 184, 195, 202, 207, 214, 216, 228, 238, 241, 242, 246, 260, 261, 265, 285, 301, 305, 309, 323, 348, 351, 352, 357, 371, 373]
Community-dwelling	[21, 43, 53, 60, 64, 68, 97, 115, 118, 137, 141, 142, 154, 215, 340, 366, 386]
Formal or informal home care	[29, 38, 46, 57, 85, 204, 213, 231, 253, 286, 359]
People in need of care are part of the target group	[221, 233, 281, 367, 375]

Table 2-A6: Citations of section 2.4.4: Target groups – Life expectancy as an exclusion mechanism

Citation element	Citation
Life expectancy as in inclusion or exclusion criteria	[1, 2, 6, 25, 28, 30, 42, 50, 57, 62, 63, 69, 80, 81, 86, 87, 92, 97–103, 106, 107, 110, 116, 122, 123, 130, 132, 141, 155, 165, 166, 187, 188, 191, 201, 205, 206, 226, 248, 254, 263, 264, 266, 286, 289, 290, 297, 307, 313, 315, 322, 323, 326, 328, 334, 344, 345, 360, 366, 367, 377, 378, 400, 404]
Only patients with a life expectancy of ≤ 12 months	[2, 6, 25, 28, 30, 42, 50, 62, 87, 97, 98, 100–103, 106, 107, 110, 116, 165, 166, 191, 206, 226, 254, 263, 264, 289, 290, 297, 307, 313, 315, 322, 334, 345, 360, 365, 400, 404]
Only patients with a life expectancy of ≤ 24 months	[122, 123, 155, 266, 286, 344, 366]
Surprise question	[25, 30, 50, 87, 97, 100, 101, 107, 110, 123, 191, 226, 254, 263, 264, 266, 289, 297, 307, 313, 315, 334, 344, 345, 400, 404]

Table 2-A7: Citation of section 2.4.4: Target groups – Advance care planning status

Citation element	Citation
Limitation regarding ACP status	[18, 27, 31, 41, 43, 79, 86, 89, 102, 112, 123, 133, 136, 142, 145, 148, 150, 152, 164–166, 175, 176, 181, 184, 189, 200, 205, 209, 223, 237, 238, 263, 275, 280, 285, 290, 297, 319, 323, 324, 331, 332, 334, 343, 355, 363, 368]
No current ACP document existed or health proxy was available	[18, 27, 79, 86, 89, 102, 112, 136, 142, 150, 152, 164–166, 184, 200, 205, 209, 237, 263, 275, 280, 285, 290, 297, 319, 323, 324, 355, 363, 368]
Health care proxy necessary	[41, 43, 123, 145, 148, 175, 176, 181, 189, 223, 238, 331, 332]
No advance directive but a health proxy	[31]
Advance directive required	[343]
Engaged in ACP	[133]
Prior participation in an ACP study was an exclusion criteria	[89]

Table 2-A8: Citations for section 2.4.4: Target groups – Limited diversity and accessibility

Citation element	Citation
Ethnicity	[7, 9, 27, 38, 64, 97, 106–108, 110, 123, 138, 153, 154, 197, 224, 227, 234, 250, 268, 281, 291, 294, 299, 320, 327, 332, 333, 341, 384, 390]
African Americans	[38, 153, 154, 227, 291, 320, 327, 332, 384]
Latino population	[27, 106–108, 110, 197, 224, 250]
Chinese American	[138]
Korean American	[268]
Aboriginal participants	[7, 64, 281]
Undefined underrepresented groups or sensitive to racial and ethnic minorities	[9, 123, 294, 299]
Oversampling of African American and Latinos	[234]
Two sites primarily serving African American and Latino populations	[390]
Group characteristics	[3, 16, 20, 121, 136, 180, 184, 190, 199, 213, 230, 274, 275, 338, 346, 388, 408]
Veterans	[121, 136, 230, 275, 346]
Students	[20, 180]
Women	[388, 408]
Older, single parents	[190]

Homeless and low-income older people	[184]
Homeless	[338]
Medicare beneficiaries	[213]
People who would benefit from an advance directive	[3]
High risk of hospitalization	[16]
Frequent hospital attenders	[274]
Member of an employer-union health fund	[274]
Exclusion criteria related to language barriers or cognitive abilities	[7–10, 14, 15, 18, 21, 23, 27, 30, 34–36, 41, 43–45, 48, 50–52, 56–60, 68, 75, 76, 83, 86, 87, 91–93, 97–103, 105–115, 121, 122, 131, 135, 136, 140, 141, 144–148, 150, 151, 154–156, 160, 162, 171, 174–177, 181–186, 189–191, 194–196, 200, 201, 204, 208, 209, 211, 215, 220, 222–224, 227, 233, 235, 237, 246, 251, 253, 254, 256, 257, 262–264, 266, 275, 277, 278, 280, 281, 283, 291, 292, 294, 297, 300, 301, 303, 307, 308, 310, 311, 315, 318, 320, 321, 323, 326, 328, 330, 331, 333, 335, 336, 338, 339, 341, 345–349, 351–353, 356–361, 365, 367, 369, 370, 378, 379, 381–384, 386, 391, 393, 395–399, 403–406, 408]
Exclusion due to language barriers	[8–10, 14, 15, 18, 23, 27, 30, 34–36, 44, 56–60, 75, 76, 83, 86, 87, 91–93, 97–100, 102, 103, 105–115, 121, 131, 136, 140, 141, 144–148, 150, 151, 154–156, 162, 171, 174, 175, 177, 181–183, 185, 186, 189–191, 194, 195, 200, 201, 204, 208, 209, 211, 215, 220, 222–224, 235, 237, 246, 251, 253, 254, 256, 257, 262–264, 266, 275, 278, 280, 283, 291, 292, 294, 297, 300, 301, 307, 308, 310, 311, 315, 318, 320, 323, 326, 328, 330, 333, 335, 336, 338, 339, 341, 345, 347, 349, 351–353, 357, 359–361, 367, 369, 370, 378, 379, 381–384, 386, 391, 395–399, 403–406, 408]
Translation support	[35, 160, 224, 277]
Exclusion due to cognitive impairments	[7, 14, 21, 27, 41, 43–45, 48, 50–52, 56, 59, 60, 68, 83, 86, 92, 97, 100–103, 106–109, 111, 112, 114, 115, 122, 135, 141, 144, 145, 148, 154, 176, 181, 184–186, 189, 190, 195, 196, 200, 215, 220, 227, 233, 237, 251, 256, 262–264, 275, 280, 281, 291, 303, 307, 308, 310, 311, 321, 326, 330, 331, 333, 336, 338, 345, 346, 348, 349, 351, 352, 356, 358, 359, 365, 367, 369, 378, 379, 381, 382, 391, 393, 395, 406]
Support by a caregiver allowed	[204]
Patients without cognitive impairment excluded	[99]

Table 2-A9: Citation for section 2.4.5: Delivery approaches and intervention components

Citation element	Citation
For care provers only	[2, 12, 13, 19, 24, 47, 49, 61, 62, 66, 70, 72, 75, 88, 104, 126, 127, 129, 133, 161, 170, 179, 195, 197, 199, 206, 214, 229, 239, 240, 243, 264, 271, 343, 354–356, 372, 377, 387, 404]
Intervention not developed yet	[50]

Table 2-A10: Citations for section 2.4.5: Delivery approaches and intervention components – Delivery approach and intervention intensity

Citation element	Citations
Individual setting	[1–8, 10, 11, 14–16, 18, 22–37, 39–49, 51, 54, 55, 57–60, 62, 63, 65, 67–69, 71, 73, 74, 76–84, 86–103, 105–126, 128–130, 132–136, 139–149, 151–164, 166–169, 171–194, 196, 198, 200–205, 208–213, 216–219, 221–237, 241, 243, 244, 246–263, 265–267, 270, 272–281, 284–287, 289–291, 293–318, 320–328, 330–339, 341, 342, 344–350, 352, 353, 357–364, 366–373, 375–379, 385–408]
(Partly) provided in group setting	[8, 9, 17, 20, 21, 33, 38, 53, 56, 64, 131, 137, 138, 165, 214, 215, 219, 220, 245, 268, 282, 283, 288, 319, 329, 340, 351, 362, 374, 380–384, 403]
Family members or other close people included	[1, 2, 5–7, 14, 15, 22, 26, 28, 34, 35, 38, 41, 43–45, 52, 57–60, 62, 63, 65, 68, 69, 71, 73, 74, 76, 77, 79–82, 84, 86, 91, 93, 94, 97, 101, 105, 107, 109, 111, 113, 114, 118–121, 124, 128, 132, 141, 144, 145, 150–152, 159, 162, 163, 165–167, 169, 173, 176–181, 183, 186–191, 200, 202, 204, 205, 208, 210–213, 216–218, 221–225, 228, 230, 233, 235–238, 241, 244, 245, 251, 255–257, 259–261, 263, 265, 266, 269, 276, 281, 282, 284–286, 289, 290, 297, 300, 302, 305–307, 309, 312–318, 320–323, 325, 326, 330–336, 339, 341, 344, 346, 352, 353, 359–361, 363, 364, 366, 371, 374, 378, 380, 381, 383, 386, 395, 398, 399, 401, 403, 407]
Single session	[17, 18, 20, 22, 24, 27, 28, 31, 34, 46, 51, 53, 67, 73, 82, 89, 95, 98, 101–103, 105, 115–117, 122–124, 128, 131, 132, 134, 136–138, 143, 144, 146–150, 153, 154, 166, 171, 176, 184, 185, 189, 200, 205, 209, 215, 224, 226, 228, 234, 235, 237, 238, 245, 250, 253, 258, 262, 264, 269, 270, 275, 280, 285, 288, 295, 306, 310, 319, 321, 328, 331, 332, 335, 338, 340–342, 345, 347, 351, 359, 364, 367–370, 374, 380–384, 390, 391, 393, 394, 396, 400, 405, 407]
Multiple sessions	[1, 4, 7–9, 15, 16, 21, 23, 25, 35–38, 41–44, 56, 58, 60, 63, 64, 68, 71, 74, 76–78, 83–86, 90, 92, 97, 100, 103, 106–114, 118, 120, 121, 130, 139–141, 151, 152, 155, 156, 158, 162–165, 167, 168, 173, 174, 177, 178, 180, 183, 186–188, 190, 191, 196, 202, 207, 208, 210–213, 219–223, 231–233, 242, 244, 247, 251, 254–257, 261, 265, 267, 272–274, 276, 278, 281, 282, 284, 286, 289, 293, 294, 299, 300, 302, 307–309, 312, 314, 315, 318, 320, 322, 323, 325, 329, 333, 334, 336, 339, 344, 350, 357, 358, 360–362, 365, 366, 371, 373, 375, 378, 385, 386, 395, 399, 401, 403, 406, 408]
Frequency of delivery could not be determined	[2, 3, 5, 6, 10–14, 19, 26, 29, 30, 32, 33, 39, 40, 45, 47–50, 52, 54, 55, 57, 59, 61, 62, 65, 66, 69, 70, 72, 75, 79–81, 87, 88, 91, 93, 94, 96, 99, 104, 119, 123, 125–127, 129, 133, 135, 142, 145, 157, 159–161, 169, 170, 172, 175, 179, 181, 182, 192–195, 197–199, 201, 203, 204, 206, 214, 216–218, 225, 227, 229, 230, 236, 239–241, 243, 246, 248, 249, 252, 259, 260, 263, 266, 268, 271, 277, 279, 283, 287, 289–292, 296–298, 301, 303–305, 311, 313, 316, 317, 324, 326, 327, 330, 337, 343, 346, 348, 349, 352–356, 363, 370, 372, 376, 377, 379, 387–389, 392, 397, 398, 402, 404]
Frequency of delivery could not be determined, but intervention provider available on demand or 24/7	[91, 96, 370]
Provider available on demand or 24/7 in total	[4, 63, 77, 91, 96, 118, 284, 370]

Table 2-A11: Citation for section 2.4.5: Delivery approaches and intervention components – Intervention components

Citation element	Citation
Conversation/interview	[1, 3–7, 9, 11, 14–18, 21–26, 28, 29, 31–37, 41, 42, 44, 46, 52, 54–56, 58–60, 63, 65, 67, 68, 71, 73, 74, 76–78, 81–87, 90–92, 94, 96, 97, 100, 101, 103, 107–111, 113, 114, 116–121, 124, 125, 132, 134–136, 141, 144, 151–156, 158, 160, 163, 165–168, 173–175, 177, 178, 180, 181, 183, 184, 186–188, 191–194, 198, 202, 205, 207, 208, 210, 216, 220, 222–226, 228, 230–233, 235, 236, 241, 244, 245, 247, 249–252, 254–258, 260, 261, 263, 264, 267, 269, 270, 275, 276, 278, 281, 284, 287, 289–291, 293–295, 297–302, 304, 306–309, 312–323, 325, 326, 328, 331–339, 341, 342, 344, 345, 350, 351, 357–362, 364–367, 370, 371, 375, 378, 385, 386, 389, 394, 395, 397–403, 406–408]
Training/coaching for intervention providers	[1–7, 9, 11, 12, 15, 17, 19, 20, 22–25, 29–34, 37, 38, 41, 43–45, 54–57, 59, 60, 62, 65, 67, 68, 70, 72–74, 76–78, 82, 83, 85–88, 90–92, 94, 95, 98–101, 104–108, 110, 111, 113, 114, 116, 117, 119, 120, 125–127, 133–136, 141, 144, 148, 150, 152–155, 158, 159, 162, 166–170, 172–174, 177, 179, 181–183, 186, 187, 191–195, 197, 198, 200, 202, 205, 207, 210, 213–216, 218, 221–226, 230, 231, 233, 235, 241–245, 249–254, 256–258, 260, 261, 264–267, 269–273, 276, 281, 286, 289, 290, 293–295, 297–301, 303–307, 309, 312–315, 319–324, 326, 331–334, 336–339, 341–345, 354, 357, 358, 361, 362, 365, 366, 371, 373, 375, 378, 382, 384, 385, 389, 392, 394, 395, 397–399, 403, 408]
Written information, e.g. brochures, flyers, patient letters, wallet cards for patients	[4, 18, 24, 30, 41, 42, 45, 48, 51, 54, 57, 59, 60, 64, 85, 90, 91, 95, 97, 106–108, 110, 112, 113, 123, 128, 135, 136, 141, 142, 144, 149–154, 164, 165, 169, 175, 176, 187, 188, 202, 205, 208, 211, 212, 220, 221, 223, 237, 244, 250, 251, 253, 256, 261, 262, 264, 270, 272, 277, 282, 289, 290, 292, 299, 300, 309, 310, 312, 313, 319, 322, 337, 338, 351, 358, 368, 370, 378, 382, 394, 398–400, 403, 405, 408]
Theoretical foundation of the intervention	[2, 4, 5, 8, 11, 12, 14, 17, 19, 20, 28, 38, 40–43, 61, 64, 78, 83, 84, 88, 93, 94, 100, 112, 115, 121, 126, 136, 146, 151, 153, 154, 162, 163, 171, 174, 184, 190, 198, 208, 211, 233, 235, 239–241, 248, 253, 262, 266, 272, 273, 280, 286, 295, 299, 302, 307, 313, 318, 324, 330, 332–335, 340, 341, 346, 348, 349, 353, 376, 378, 386, 388, 395, 401, 405]
Video	[10, 17, 43, 57, 64, 89, 98, 99, 101–103, 105, 115, 137, 140, 145, 146, 148, 149, 159, 171, 175, 189, 193, 200, 208, 209, 218, 220, 238, 242, 246, 248, 265, 268, 280, 281, 289, 292, 299, 300, 319, 330, 340, 358, 369, 376, 378, 389–393, 400, 406]
Online media, computerized, website	[8, 9, 14, 17, 64, 71, 93, 112, 122, 123, 142, 143, 145–148, 189, 201, 211, 213, 219, 227, 246, 253, 256, 273, 288, 289, 292, 296, 311, 327, 346, 348, 349, 363, 376, 379, 388, 389, 394]
Workbook (written processing of materials)	[9, 17, 22, 56, 58, 60, 79, 80, 87, 89, 116, 142, 147, 156, 176, 190, 200, 210, 228, 233, 255, 257, 266, 275, 280, 290, 344, 345, 347, 352, 353, 363, 378, 396, 397, 408]
Lecture/presentation/webinar	[21, 27, 43, 53, 64, 103, 136, 137, 148, 168, 182, 274, 280, 281, 291, 329, 368, 374, 390, 391, 393]
(Video) case vignettes, hypothetical scenarios	[38, 41, 43, 71, 76, 79, 83, 175, 176, 185, 236, 237, 244, 258, 359, 379]

Game (board game, card game, computer game)	[93, 162, 196, 215, 282, 283, 378, 380–384]
Unspecified tool for care provider without information for delivery to the patient	[2, 126, 129, 133, 172, 343, 354–356, 387, 404]
Workshop	[20, 69, 131, 138, 282, 286, 288, 329, 340]
App/patient portal	[39, 40, 48, 94, 254, 279, 310, 405]
Interactive tasks, role play	[17, 25, 43, 373, 376]
Written information for relatives or other close people	[112, 150, 169]
Case conference incl. relatives or other close people	[45, 128, 285]
Simulation of a conversation	[123, 143, 180]
Community trip	[21]
Quiz	[43]
Values inventory	[234]
Card for location of ACP documents	[164]
Meditation	[165]
Cartoon	[176]
To-do list	[262]
Lunch	[268]

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3 Let's talk about death, dying, and what matters most to you in life: Pretest and piloting of a translated and adapted conversation game

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3.2 Abstract

Objective: This study aimed to pretest and pilot the German version of the *Hello* conversation game (German: *Hey du*) to assess its comprehensibility and acceptability. Like the original, *Hey du* is designed as a low-threshold method to empower people of almost all ages and health conditions to engage in advance care planning (ACP), particularly targeting young/healthy people for whom there are currently few or no ACP programmes.

Methods: The conversation game was systematically translated into German using the TRAPD process and cognitively pretested in 12 interviews. Subsequently, two observational studies were conducted: *Hey du* was used in 1) a nursing school ($n = 16$) and 2) with groups of family and friends ($n = 50$). After completing the game, participants were surveyed regarding the game's acceptability and comprehensibility.

Results: The results of the cognitive pretest and the observational studies show that the conversation game was acceptable and comprehensible in both settings. Most of the participants (>92%) reported that *Hey du* helped them come to terms with their own wishes and preferences for medical and nursing care and that they felt comfortable playing the game.

Conclusion: *Hey du* has the potential to motivate and empower people to deal with ACP.

Innovation: *Hey du* is the first scientifically supported gamification approach in Germany

to introduce ACP to people for whom no systematic ACP programs exist. The game provides a safe forum for people of almost all ages and health conditions to discuss their values regarding life, death, dying and what matters most.

Keywords: Advance care planning, gamification, acceptability, comprehensibility

3.3 Introduction

Many people find it difficult to talk about the end of their own lives and their own wishes and preferences for medical and end-of-life care. Addressing the end of life with family and friends is often perceived as challenging [1, 2], for example because of generational differences, different beliefs, and cultural taboos [3]. The aim of advance care planning (ACP) is to overcome this barrier by empowering and motivating people to address their individual wishes and preferences for their own medical and nursing care in the event that they are unable to give consent. These wishes and preferences should be discussed with loved ones and/or service providers and ideally documented in writing [4].

Knowing and communicating one's wishes and preferences for medical and nursing care is important for people of all ages and health conditions. While it may be difficult for young and healthy people (YHP) to imagine themselves in a serious health situation, it is important to be able to take into account the wishes and preferences that exist at that moment [5]. For older and already (chronically) ill people, there are a number of effective ACP interventions to guide them through the empowerment process: for example, guided conversations such as Respecting Choices[®] [6] and 'Let me decide' [7]. For ACP for YHP, however, there is little evidence or research to date, although it is recommended to go through the ACP process before the onset of a serious illness and to be prepared in the event of an acute emergency [2]. A key part of the ACP approach is that the process of considering and expressing wishes and preferences can and should be iterative, because wishes and preferences can evolve over time and with changing circumstances [4].

Even if planning for their own medical and long-term care before death might be less urgent for YHP at first sight, increasing their awareness of ACP can have a positive impact in different ways: Engaging in ACP as a young adult could improve their own ACP process as they age. In addition, many people accompany family members, for example, as they age and at some point take on the role of caregiver. In this role, younger people can play an important part in initiating and facilitating ACP discussions with the person concerned [5]. It is important to initiate and conduct ACP discussions in order to learn about the wishes and preferences of the person concerned. Without prior discussion of wishes and preferences,

providing information about the person's wishes can create a great deal of uncertainty. This uncertainty is often accompanied by psychological distress for the people involved [8], who are often relatives or others close to the person [9]. To go through an ACP process for oneself or to support others in doing so, there must be a willingness to engage with the topic.

Studies have shown that gamification is an effective approach to getting people of all ages to engage with emotionally difficult topics [10, 11]. In the international context, a systematic review by Liu, Zhao, Yang, Chan [12] shows that gamification can be an effective way to support and initiate ACP conversations due to the safe forum that the game provides for such sensitive discussions [12]. One of the games included in the systematic review [12] is *Hello*. *Hello* is a conversation game in which the players are encouraged to talk about their values in life, death, dying, and what matters most to them [13]. The game is currently used primarily in the US, although it has been translated into Spanish, Czech, Thai, and Korean. Studies have shown that *Hello* is an effective, inexpensive, and safe approach to effectively engage people in conversations and discussions about the topics addressed in the game [13–15].

To our knowledge, there are no studies in Germany that test the gamification approach for ACP and/or aim to motivate and empower YHP to engage in ACP. To date, ACP services in Germany have mainly focused on the elderly or sick (e.g. Patientenverfügungsgesetz [16], the Hospice and Palliative Care Act [17], *Behandlung im Voraus planen* [18], the STADPLAN project [19]).

The aim of this study was twofold: The first aim was to translate the conversation game *Hello* to German, adapt it if necessary to the German context, and test its acceptability and comprehensibility via cognitive pretesting. Secondly, two observational studies were conducted to gain further insight into the acceptability and comprehensibility of *Hey du*, the German version of *Hello*. Considering the important role that culture plays in communication about end-of-life issues, it is important to consider potential differences between nationalities [20] [21]. Furthermore, this study was designed to evaluate whether adaptations are needed to adapt the game to the German context in addition to the language translation.

3.4 Methods

The methodological approach of this study is divided into three steps:

- 1) The conversation game *Hey du* was systematically translated into German (see chapter 3.4.2).

2) An initial assessment of the acceptability and comprehensibility of the translation was carried out in a cognitive pre-test (see chapter 3.4.3).

3) Two observational studies were conducted to gain further insight into acceptability and comprehensibility (see chapter 3.4.4).

3.4.1 Description of the Conversation Game

The conversation game *Hey du* is the German version of the commercially available English version of the conversation game *Hello* [22]. In the game, players answer 32 questions about their wishes and preferences regarding dying and end-of-life care (see Table 3-1). First, they answer these questions in writing for themselves and then discuss them in the group (2–5 people). Players can award ‘Thank You’ chips for responses they find thought-provoking, heart-warming, or otherwise worthy of expressing gratitude for sharing.

Table 3-1: Example questions from *Hey du*

Question number	Question
No. 4	Name the three-person committee who should be consulted on any decisions made about whether to continue life-saving care if you can't communicate?
No. 14	When you think about care at the end of your life, what do you worry more about: <ul style="list-style-type: none">• Not getting enough care• Getting overly aggressive care• Other:
No. 21	What music do you want to be listening to on your last day alive?
No. 27	I want my doctor to be focused on maximizing: <ul style="list-style-type: none">• The length of your life• The quality of your life• Other:

3.4.2 Translation Process

For the translation of the game *Hey du*, the Translation, Review, Adjudication, Pretest, Documented (TRAPD) process was used [23], to ensure a structured and transparent translation process which could be replicated. In the translation phase, three groups (with two members per group) produced independent translations. These translations were then rated by three members of the research team during the review phase and merged into a

single translation. In the adjudication phase, the translation was compared to the original. This was followed by a cognitive pretest. The entire process was documented.

3.4.3 Cognitive Pretest

Aim of the cognitive pretest

The aim of the cognitive pretest was to obtain an initial assessment of the acceptability and comprehensibility of the translated conversation game *Hey du* and to explore potential adaptations needed in addition to language translation. The cognitive pretest included the think-aloud technique, probing techniques and paraphrasing to learn more about the cognitive response process of users [24]. To conceptualize acceptability, we used the theoretical framework of acceptability (TFA) [25], which defines acceptability as a multi-faceted construct that reflects the extent to which people assess an intervention to be appropriate.

Recruitment

A convenience sample of individuals aged 18 and older was invited to participate in the cognitive pretest. Participants were recruited from the interviewer's personal network. The interviewers were motivated to approach people from their own age group as well as from their parents' generation in order to obtain a sample that was as age-diverse as possible. The participants first received information about the study in a personal conversation. If they were interested in participating, they then received more information about the study and a consent form in writing. The consent form was signed by the participants before the study was conducted.

Data collection

For the cognitive pretest, $n = 12$ cognitive interviews were conducted. The interviews were conducted by trained graduate students under the supervision of the research team (JJ, JKN). During the cognitive pretest, participants were presented with each of the game questions one at a time. Participants were asked to use the think-aloud technique and to explain how they understood the question they had just been asked and what information they thought the question was trying to elicit. Questions that were considered potentially difficult to understand should also be paraphrased. Participants were further asked to reflect on the acceptability of the questions and the gaming process as a whole. Age, gender, and previous experience with ACP were also collected. At the end of the pretest, participants were given the opportunity to review all questions and the game instructions again and make suggestions for changes.

Data analysis

The pretests were transcribed using Kuckartz's [26] methods of transcription and then analysed qualitatively. The transcripts were analysed using directed content analysis [27] using Excel 2021 to identify problems in understanding the questions and the need for changes.

3.4.4 Observational Studies

Aim of the observational studies

The aim of the observational studies was to gain further insight into the acceptability using three component constructs of the TFA: (1) perceived effectiveness, defined as the extent to which *Hey du* is considered likely to achieve its intended purpose; (2) affective attitude, defined as a person's feeling about the intervention; and (3) self-efficacy, which is a person's confidence that he or she can perform the expected actions [25]. Furthermore we explore the comprehensibility of *Hey du*.

Study design

We evaluated the acceptability and comprehensibility of *Hey du* during two observational studies, involving populations that tend to be younger and healthier than the current main target groups of evaluated ACP interventions. The first study was conducted with nursing students to test the acceptability and comprehensibility of using *Hey du* in healthcare education. It is possible that *Hey du* not only changes personal ACP behaviour, but also has a positive effect on the preparation and conduct of ACP discussions by healthcare professionals. The second study was conducted in a family/friendship context.

Recruitment

Study 1: A nursing school that had already shown interest in the *Hey du* conversation game was invited to participate in the study. The contact person for the study team at the school selected a class of nursing students whose curriculum would be a good thematic fit for the conversation game according to the nursing school. Students in the selected class were informed the week before the game event that their class would be participating in a game event during class time for approximately three hours. They were introduced to the game and the scientific monitoring for the game event. After the short presentation, the students were given the written study information and consent forms. Participation in the game *Hey du* was mandatory as part of the teaching curriculum, but the students were given the option to participate in the scientific survey or not. All students agreed to take part in the scientific survey. The signed consent forms were collected at the game event.

Study 2: A convenience sample was recruited. The study team approached people in their personal environment (family members, friends and friends of friends who were interested in participation), and invited them to participate in the study. If they were interested, they were sent the study information and the informed consent form. The signed consent form was collected before the start of the game event.

Outcome measure

A paper-based questionnaire was used to assess comprehensibility and acceptability. Participants were asked to indicate, on a 4-point scale (*strongly agree* to *strongly disagree*), the extent to which they agreed with statements about the *Hey du* conversation game.

Comprehensibility

Comprehensibility was measured by assessing the extent to which participants agreed that the questions asked in the game were understandable to them. In a free text field, participants could indicate which questions they thought were hard to understand or not understandable at all.

Acceptability

When asked about the acceptability of the game, participants indicated the extent to which they agreed with statements about the following four aspects:

1. *Appropriateness for discussing wishes and preferences regarding medical and nursing care at end of life* (TFA: perceived effectiveness). Participants indicated the extent to which they agreed with the statement that the game was appropriate for discussing a sensitive topic such as dealing with one's own wishes and preferences regarding medical and nursing care at the end of life.
2. *Helpfulness in understanding one's own wishes and preferences regarding medical and nursing care at end of life* (TFA: perceived effectiveness). Participants indicated the extent to which they agreed with the statement that the game helped them come to terms with their wishes and preferences regarding their own future medical and nursing care.
3. *Comfort while playing* (TFA: affective attitude). Participants indicated the extent to which they agreed with the statement that they felt comfortable while playing *Hey du*.
4. *Potential use of the game in families or with friends or initially with strangers* (TFA: self-efficacy). Participants indicated the extent to which they agreed with the statement that they could imagine playing the game (1) with family members, friends, or other close people; or (2) with people who were strangers at the beginning of the game.

Data collection

Study 1: At the beginning of the game event, the game and the study procedure was explained to the students in detail. The game was played in two groups of five and one group of four. After the game, the students ($n = 14$) were given a short survey about the comprehensibility and acceptability of the game. In addition, there was a semi-structured feedback session for which field notes were prepared. In the feedback session, participants were asked to provide feedback on the following topics: (1) general game experience, (2) use of the game in the family environment and/or with strangers, (3) impact of *Hey du* on their own ACP behaviour, and (4) use of *Hey du* in their future work as nurses. Eight weeks after the game, they were given another short survey by the contact person at the nursing school. In this survey, they were asked whether they found *Hey du* helpful in understanding their own wishes and preferences for medical and nursing care in the event of incapacity and whether they thought *Hey du* was an appropriate format for this sensitive topic.

Study 2: Study 2 used a convenience sample ($n = 50$). Family members and groups of friends were invited to play *Hey du*. The games took place in the participants' private spaces. As in study 1, participants were surveyed immediately after completing the game and again four weeks later.

Data analysis

Frequencies and mean scores of the data were calculated for comprehensibility and acceptability with STATA SE15. Missing data were not imputed. The field notes of the feedback session from study 1 were analysed using directed content analysis [27] with regard to the topics discussed in the feedback session: (1) general game experience, (2) use of the game in the family environment and/or with strangers, (3) impact of *Hey du* on participant's own ACP behaviour, and (4) use of *Hey du* in their future work as nurses.

3.4.5 Ethical Approval

Ethical approval was obtained from the ethics committee of the University of Wuppertal (cognitive pretest: SK/AE 230125 [15th February 2023]; study 1: SK/AE 230809 [8th November 2023]; study 2: SK/AE 230725 [14th August 2023]). All methods were performed in accordance with these approvals. Informed consent was obtained from all participants.

3.5 Results

3.5.1 Cognitive Pretest

Study population

The cognitive pretest was conducted with 12 people. Seven of the participants were female (58.3%), five were male (41.7%). The mean age was 37 years (SD = 17.49). Fifty percent of the participants had already completed ACP documents.

Results of the cognitive pretest interviews

The participants had no major problems understanding the questions. They were able to reproduce the questions in their own words and could imagine the content issues they would address when answering the questions.

Three of the 32 questions required minor changes. One question was made easier to read by inserting an extra line between two sentences, another question had a word replaced to make the question clearer, and the third question was slightly shortened. Cultural adaptations were not necessary. The questions were rated as understandable by the participants.

3.5.2 Observational Studies

Study population

Table 3-2 shows the descriptive characteristics of the study population. More than half (57.6%) of participants were female. One third (36.4%) was between 18 and 27 years of age. In study 1, the proportion of 18–27-year-olds (62.5%) was significantly higher than in study 2.

Table 3-2: Descriptive characteristics of the study population of the observational studies

	Total $n = 66$ (%)	Observational study 1 $n = 16$ (%)	Observational study 2 $n = 50$ (%)
Age group			
18–27	24 (36.4)	10 (62.5)	14 (28.0)
28–37	14 (21.2)	1 (6.3)	0 (0.0)
38–47	1 (1.5)	1 (6.39)	13 (26.0)
48–57	9 (13.6)	0 (0.0)	9 (18.0)
58–67	14 (21.2)	0 (0.0)	14 (28.0)
N/A	4 (6.1)	4 (25)	0 (0.0)
Gender			
Woman	38 (57.6)	10 (62.5)	28 (56.0)
Man	24 (36.4)	2 (12.5)	22 (44.0)
N/A	4 (6.1)	4 (25)	0 (0.0)

Comprehensibility

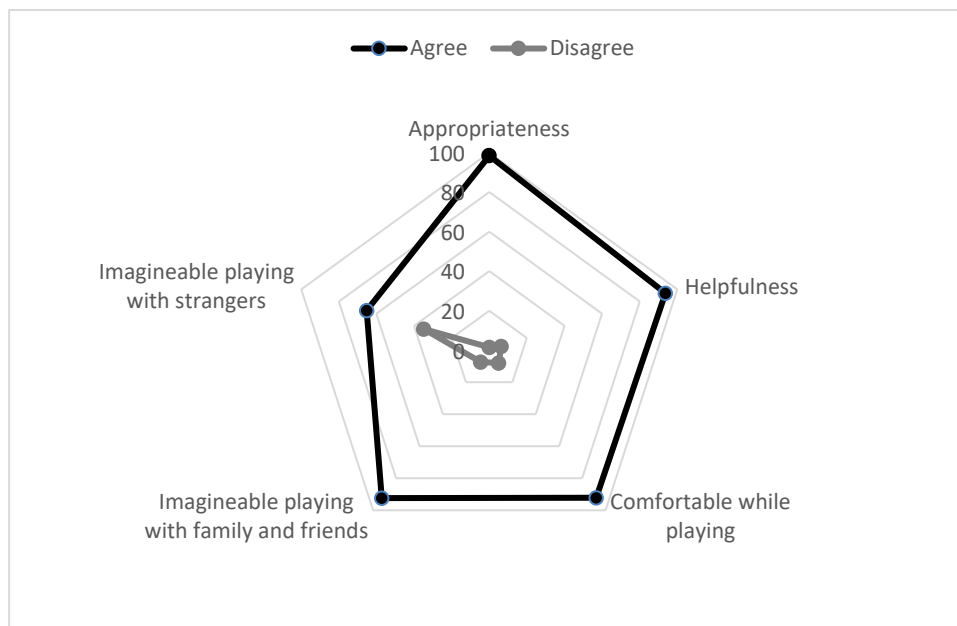
Nearly all of the participants (98.5%, $n = 65$) strongly or somewhat agreed with the statement that the questions asked in the game are understandable. Only one participant (1.5%) indicated that he or she tended to disagree with this statement. Two people said they were not sure what the term ‘non-medical facts’ meant, which appears in one of the 32 questions without further explanation. One participant stated that some questions covered similar content.

Acceptability

Figure 3-1 shows, that nearly all of the participants (95.4%, $n = 62$) strongly or somewhat agreed with the statement that *Hey du* is suitable for discussing a sensitive topic such as dealing with one’s own wishes and preferences regarding medical and nursing care at the end of life. One participant (1.6%) stated that he did not tend to agree with this statement. Most of the participants (93.7%, $n = 59$) found the game helpful in understanding their wishes and preferences for future medical and long-term care. In each study, two participants (3.2%) found the game to be not entirely helpful or not helpful at all. Moreover, 92.1% of participants ($n = 58$) stated that they fully or somewhat agreed with the statement that they felt comfortable while playing; 7.9% ($n = 5$) tended to disagree with this statement. In

addition, 92.4% ($n = 61$) of participants strongly or somewhat agreed that they could imagine playing the game with family members, close friends, or other people close to them; three people (4.6%) tended to disagree with this statement, and two (3.0%) strongly disagreed. Nearly two-thirds of the participants (65.2%, $n = 43$) agreed with the statement that they could imagine playing the game with people who were strangers to them at the beginning of the game; 24.2% ($n = 16$) stated that they disagreed with this statement and 10.6% ($n = 7$) that they strongly disagreed with this statement.

Figure 3-1: Acceptability of *Hey du*



Four topics were discussed during the feedback session. Topic 1 was general feedback on the game experience. The atmosphere of the game was described as relaxed. It was regarded as positive that a question is answered first for oneself before it is shared with others on a voluntary basis. The second topic was the use of the game in the family and with other close people. It was mentioned that the game might be a good starting point for conversations with one's own family to learn more about people's wishes and preferences. The third topic was the benefits of *Hey du* for one's ACP. It was mentioned that the game had given them ideas to think more deeply about in regard to their own end of life, death, and the wishes and preferences associated with it. It was also mentioned that the first thoughts about ACP had already been formulated in writing through the game and that the barrier to communicating this to a doctor had now been lowered. The fourth topic discussed by the nursing student participants was whether and how *Hey du* could be used with patients to facilitate access to patients for discussions about ACP. The nursing students suggested that *Hey du* would help them approach the topic of ACP with patients and saw the game as an opportunity to get to

know patients better as people. They mentioned the possibility that patients could first play the game alone or with their families and then talk to the nurse about the game.

3.6 Discussion and Conclusion

3.6.1 Discussion

The results of the cognitive pretest and the two observational studies show that the conversation game *Hey du* is comprehensible and acceptable. The vast majority of participants (>92%) in the studies stated that *Hey du* helped them to come to terms with their own wishes and preferences for medical and nursing care and that they felt comfortable playing. These results are consistent with the US studies that tested the feasibility and acceptability of the conversations using an English-version of *Hello* [13, 15, 28].

The results of our study do not replace an effectiveness evaluation of the game. Nevertheless, they show that, from the participants' point of view, there are no reservations about using *Hey du* with a group of people who are not in need of care and who are not seriously ill. Only a few adaptations were necessary to make *Hey du* comprehensible and acceptable in the German context. The results also show that the time frame necessary to play *Hey du* and to engage with the topics of ACP and end-of-life issues is appropriate, even if it is a topic that is often associated with discomfort [29]. While *Hey du* is not a holistic ACP intervention, these results suggest that it may be an appropriate tool to empower and motivate people to engage with ACP, to start reflecting and formulating their own wishes and preferences, and to learn to communicate them. This can help overcome social and cultural barriers that otherwise exist in relation to ACP [3]. *Hey du* could be a way to reach people of all ages, almost regardless of their state of health, especially people who have not yet had to deal with the topic, such as YHP. By making the game available to YHP in a systematic way it could increase their engagement and awareness of ACP and, as a result, strengthen ACP planning for their own future. As a result of the increased awareness of ACP and the empowerment of YHP, it is conceivable that the game will also lead to conversations with elderly and/or sick family members and relatives being initiated and facilitated. Possible implementation strategies should be explored in further studies.

The results of the two studies show that the use of *Hey du* is not limited to one setting or to groups of people who know each other very well and have a close relationship. *Hey du* was well received in both the family and nursing school settings. This finding is also consistent with US studies in which the original game has been successfully used in different settings and contexts (e.g. [30, 28, 14]). A study by Van Scoy et al. in 2016, however, found mixed

results when participants were asked with whom they could imagine playing *Hello*. Participants in game groups that initially consisted of strangers were more likely to say that they could not imagine playing the game with strangers. Participants who played *Hello* with people they knew were more likely to say they would not want to play the game with strangers [13]. In our study, more than half of the participants (65.2%) indicated that they could imagine playing the game with people who were initially strangers to them.

The results of the pretest and the two observational studies suggest that *Hey du*, like *Hello* in the US [13, 14], is an acceptable way for people to engage with ACP.

3.6.2 Innovation

To our knowledge, *Hey du* is the first scientifically supported, low-threshold gamification approach in Germany to introduce ACP to people of almost all ages and health conditions. Previous ACP programmes have mainly targeted older and/or (chronically) ill people [31]. The extension of the target groups is in accordance with the ACP concept, as it aims to empower and motivate people of all ages and health conditions to deal with their wishes and preferences regarding death and dying [4].

Hey du also motivates and empowers younger and healthy individuals to engage with ACP. This can improve their own ACP process as they get older and help them to start, lead, and facilitate ACP conversations with family members or close friends in the future. This can help to reduce the uncertainty associated with making medical and care decisions for another person and thus decrease the psychological stress for the person making the decision [8], who are often relatives or others close to the person [9].

3.6.3 Limitations

This study does not provide any insight into the effectiveness of *Hey du* as it is not a randomised controlled trial (RCT). This would require further, larger studies to be conducted in the future. A more detailed description of the samples demographic is not possible due to the small size in order to ensure data protection.

The generalizability of the results is limited, because participants were selected for the cognitive pretest and the observational studies using convenience sampling. In the cognitive pre-test sample, 50% of the participants had already completed ACP documents. It is possible that these people found it easier to understand the questions and rate *Hey du* as acceptable than people who had not completed ACP documents. Something similar may be true for sample 1. Due to the professional background of the students, the assessment of

comprehensibility and acceptability could be biased.

In addition, only sample 1 could be offered a structured feedback session, because sample 2 played in small groups. In order to schedule these, a feedback session had to be omitted.

Nevertheless, based on the results of the cognitive pretest and the observational studies together with the study results on the original *Hello* game from the US [13, 14], it can be concluded that the use of *Hey du* to initiate ACP conversations is acceptable and comprehensible.

3.6.4 Conclusion

This study shows that *Hey du* is an acceptable and comprehensible approach to help individuals engage in ACP and end-of-life discussions, and thus the gamification approach seems to work with ACP in Germany. To be able to make a statement about the effectiveness of the game, however, a randomised controlled trial needs to be conducted. A RCT could include the game either as an intervention or as an implementation strategy in a trial testing another ACP intervention.

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3.9 Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors used DeepL to improve the linguistic quality of the manuscript before the proofreading. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

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3.10 Conflict of interest

The authors declare that they have no conflict of interest.

3.11 Data statement

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

4 Measuring Patients' Medical Treatment Preferences in Advance Care Planning: Development and Validation of the Treat-Me-ACP Instrument – A secondary analysis of a cluster-randomized controlled trial

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4.2 Abstract

Background: Advance Care Planning interventions should be evaluated as broadly as possible to gain a holistic understanding of the Advance Care Planning process. However, validated early stage outcome instruments are lacking. Therefore, the Treatment-Preference-Measure-Advance Care Planning (Treat-Me-ACP) instrument was developed and validated as part of the cluster-randomized controlled trial STADPLAN (Study on Advance Care Planning in care-dependent community-dwelling older persons) to assess the effects of Advance Care Planning interventions on patients' medical treatment preferences.

Methods: The design of Treat-Me-ACP is based on the Emanuel Medical Directive and the Life Support Preferences Questionnaires. Using a multi-stage team approach a preliminary version of the Treat-Me-ACP was developed and pre-tested. The pre-tested instrument consists of one global medical care goal-item, five hypothetical scenarios with five hypothetical treatments, and one how would you feel-item within each scenario. A total of five scenario preference scores and five treatment preference scores can be formed. This version was subsequently applied to a subsample of the STADPLAN project (n=80) to assess patient's preferences at baseline (T0) and at 12-month follow-up (T2). The further validation steps were based on this subsample and included: (1) acceptance by using completion rate and frequencies of missing data, (2) internal consistency by using Cronbach's α to test whether it was possible to create preference scores by scenario and treatment, (3) concurrent validation examining the association between the global medical care goal-item and the preference scores and the association between the how would you feel-items and the scenario preference scores, and (4) responsiveness of the instrument to changes in preferences for life-sustaining treatments by comparing preference scores from T0 to T2 between study groups.

Results: Acceptance of the instrument was high. Results of concurrent validation indicate that the five scenarios represent the global medical care goal well. The preference scores showed an average tendency for decreasing preferences for life-sustaining treatments across

all scales for the intervention group during study follow-up.

Conclusions: The Treat-Me-ACP can be used to evaluate the dynamics of patients' medical treatment preferences in Advance Care Planning. It has been validated for care-dependent community-dwelling older persons and can be used as an additional outcome measure in evaluating the effectiveness of ACP interventions.

Trial registration: German Clinical Trials Register: DRKS00016886 on 04/06/2019

Keywords: advance care planning; patient preference; hypothetical scenario; community-dwelling older person, independent living

4.3 Background

Advance Care Planning (ACP) 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” [1]. The conceptualization of ACP has broadened to a “process of health behavior change” [2] that consists not only of actions (e.g. choosing a surrogate decision maker or documenting and communicating wishes to others), but also of personal reflection and awareness of the perceived value of different health states. The variety of behavioral changes means that the effect of ACP should be measured at various points in this process [3]. The ACP Outcome Framework which was developed in 2017 using the Delphi method provides an outcome structure for the evaluation of ACP at different stages [3, 4]. Even though the importance of evaluation at different stages is discussed in the framework [3, 4], research on ACP has focused mainly on long-term outcomes. Examples are the number of completed advance directives [5, 6] the use of life-sustaining treatments, number of hospitalizations, length of stay [7]. There are currently only a few instruments for measuring early-stage outcomes [4] like the change for awareness for ACP or dynamics of the patients' preferences. In order to be able to select appropriate outcome instruments for conducting studies, more research is therefore needed to create reliable and valid outcome measures for early stage outcomes [3]. These early measures are particularly important for the evaluation of ACP interventions, as they allow for a more in-depth explanation of the individual's process of change. Early outcomes can be used to assess the effectiveness of ACP interventions even when long-term outcomes such as hospitalizations and length of stay cannot be observed.

In this study, we aimed to develop and validate the patient-reported measure Treatment-Preference-Measure-Advance Care Planning (Treat-Me-ACP). In particular we examined

acceptance of the instrument and its internal consistency. We also focused on concurrent validation and the responsiveness of the instrument to changes in preferences for life-sustaining treatments. This measure complements the long-established effectiveness analysis of ACP interventions and will allow the study of the dynamics of patient preferences during an ACP process.

4.4 Methods

4.4.1 Study design and setting

Research context

The Treat-Me-ACP was developed, validated and used in the STADPLAN project (STudy on ADvance care PLANing in care-dependent community-dwelling older persons). The purpose of the STADPLAN project was to develop an ACP intervention for elderly care-dependent people living at home and to evaluate the effects of this complex intervention in comparison to optimized usual care. The project comprised a two-arm cluster-randomized controlled trial (c-RCT) with a 12-month follow-up (German Clinical Trials Register: DRKS00016886 on 04/06/2019). The intervention was an adapted version of the patient-centered ACP program Respecting Choices® [8], and was conducted at the home care service level and the patient level [9]. Alongside effectiveness and process evaluation, a health economic evaluation of the intervention was conducted [9, 10]. Twenty-seven home care services in three German study regions (Oldenburg, Halle [Saale], and Lübeck) participated and were randomized [9, 11]. Recruitment of home care services took place from April 2019 to December 2019. First patient in was 28th May 2019, last patient out was 11th January 2021. More information about the project can be found in the study protocol [9, 10], the development of the intervention [12] as well as on the main results, including the process evaluation [11, 13].

Ethical approval was obtained from the ethics committees of the Medical Faculties of the Universities of the Martin Luther University Halle-Wittenberg (no. 2019-045), the Carl von Ossietzky University Oldenburg (no. 2019-024), and the University of Lübeck, Germany (no. 19-080) in a joint approval. All methods were performed in accordance with this approval.

Study population

The study population of the c-RCT STADPLAN included 380 patients aged 60 years or older. The study was originally designed to include patients aged 65 years or older. The minimum age was lowered to 60 as a result of the previous pilot study, as the home care

services stated that it was important not to exclude "younger" patients. Informed consent was obtained from all patients and their legal guardians. Clients of home care services who were assigned to a care grade (as assessed by expert raters of the Statutory Health Insurance) and rated to have a life expectancy of at least four weeks were included. In addition, adequate knowledge of German and the cognitive ability to follow the intervention and data collection were required. Cognitive ability to follow the intervention was assessed using the Dementia Screening Scale (DSS) [14]. Patients with a score <3 were included in the study. Patients with a score of 3 to 5 were included if the trained nurse from the participating home care service considered the patient to be cognitively able to follow the intervention [9, 11].

This validation study used a convenience sample of 80 patients from the participants in the STADPLAN c-RCT: 40 patients of 13 home care services assigned to the intervention group (IG), 40 clients of 12 home care services assigned to the control group (CG). Patients were selected by the research assistants who conducted the interviews depending on whether they felt that an additional survey using the Treat-Me-ACP could be conducted without imposing a heavy burden on the patient. The analyses of this validation study included 64–80 cases each. On average, data from 69 patients ($SD = 2.2$) were included in the analyses. The recruitment target of the main study was $n = 960$. The recruitment target for this validation study was 12.5% ($n = 120$) of the patients included in STADPLAN. The recruitment goal was limited by available staff resources.

Instrument development and pre-test

Step 1: Development of a preliminary version

The Treat-Me-ACP was developed during the STADPLAN project. The design of the Treat-Me-ACP is based on the Life Support Preferences Questionnaires [15, 16] and the Emanuel Medical Directive [17], which were identified in a literature review. The instruments are the only ACP preference instruments known to us that have been scientifically studied. Both instruments were translated into German independently by two researchers using the multi-stage translation–review–adjudication–pre-test–documentation (TRAPD) team approach [18]. Within a project meeting, each translated element was rated by interdisciplinary research team members (RS, KS, AB, ÄK, FH, GM, SK) according to its relevance, acceptability, and appropriateness for the German healthcare context. The research team was qualified to assess the elements because of its composition of an epidemiologist, health services researcher, nursing scientists, and nurse. To reach an agreement, at least one member of the study team from each site had to vote in favor of including the translated element. Thus, an approved item always received the approval of more than 50% of the

research team members. Unlike Gilbert and Prion 2016 [19], we chose this threshold in order to include a larger number of items in the testing. Elements that received consensus were used for a preliminary version of the instrument. The result was an instrument with nine scenarios. The preliminary version was ordered by increasing intensity of health limitations and translated into patient-friendly language by experts.

Step 2: Assessment of comprehensibility, acceptability, and feasibility

Pre-testing of the preliminary version of the Treat-Me-ACP was conducted in two rounds of interviews with probing questions to test for comprehensibility, acceptance, and feasibility [20, 21]. The results of the interviews were evaluated and discussed within the research team and adjustments were made as needed.

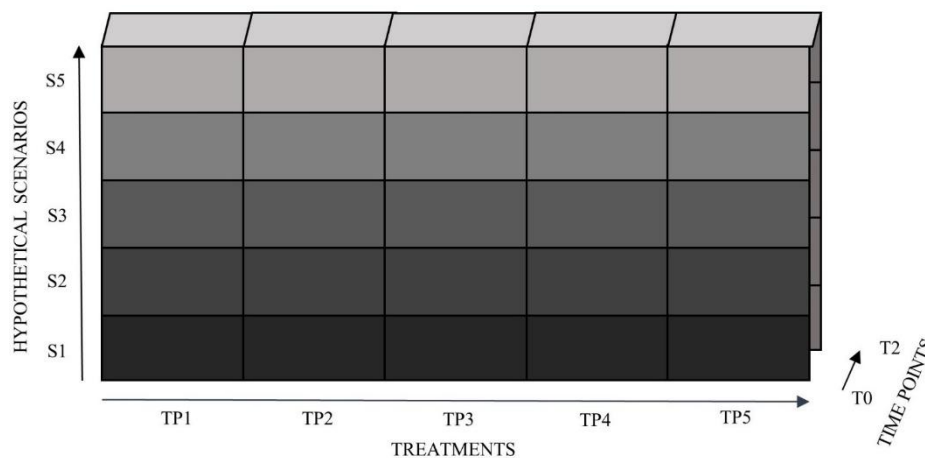
Step 3: Final interview round with adapted instrument

The final step was to test the revised instrument in interviews with probing questions to test for comprehensibility, acceptance, and feasibility again. The final adjustments were made after consultation within the research team (see Additional file B1).

Final instrument

The final Treat-Me-ACP contains one global medical care goal-item and five scenarios: S1 (current health status), S2 (advanced dementia), S3 (stroke with paralysis), S4 (stroke with six weeks coma), S5 (incurable brain tumor) (see Additional file B2). Scenarios are roughly sorted by severity of the associated health limitations, with the most severe as the final scenario. Figure 4-1 shows a schematic diagram of the Treat-Me-ACP.

Figure 4-1: The Treat-Me-ACP instrument (modified version based on Schwartz et al. 2004 [17])



The Treat-Me-ACP items were used to understand the dynamics of patient preferences over the follow-up period and the differences between both study groups. We assumed that

preferences could change meaningfully through an ACP intervention. Therefore, we expected to see greater changes in preference scores in the IG of the STADPLAN c-RCT than in the CG.

For each scenario, patients are asked how they would feel if they spent the rest of their lives in this state (how would you feel-item) and what their treatment preference (TP) would be: TP1 (antibiotics in the case of a severe infection), TP2 (cardio pulmonary resuscitation in the case of cardiac arrest), TP3 (cholecystectomy in the case of a gallbladder infection), TP4 (temporary artificial nutrition if they are unable to eat and drink independently), and TP5 (permanent artificial nutrition if they are unable to eat and drink independently). Response options were presented on a 5-point Likert scale (“definitely not” to “definitely”) supplemented by “not applicable” and “I do not wish to answer”.

The global medical care goal-item includes the question of whether patients prefer care or treatment that allows them to live as long as possible but may lead to health problems or care or treatment that might shorten their life but potentially reduce the risk of major health problems.

Psychometric evaluation

Data collection

For psychometric evaluation of the Treat-Me-ACP, a secondary analysis of the health economic evaluation sub-study data was conducted. In addition to the Treat-Me-ACP, information was collected on patients' sociodemographic characteristics, current health status, and use of health services in the past three months.

Data were collected at two time points of the c-RCT: T0 (baseline) and T2 (12-month follow-up). The instrument was the last part of a case report form to be completed during a structured face-to-face interview conducted by trained research assistants in patients' homes. Each interview was scheduled individually. A family member or close friend was allowed to participate. Patients could ask comprehension questions at any time during the interviews. The research assistance trained for the STADPLAN project were qualified to answer these questions. We report methods and results of the psychometric evaluation according to the recommendations set out in Streiner et al. 2014 [22].

Preference scores

Following Schwartz et al. 2004 [17], two types of preference scores were created and used in this validation study: (1) preference scores across treatments within a scenario (scenario preference score, or SPS), indicating patients' preference for a given intensity of life-

sustaining treatments in the respective health status; and (2) preference scores for a specific treatment across scenarios (treatment preference score, or TPS), indicating patients' overall preference for a given intensity of life-sustaining treatment across the five health states (see Table 4-2). Thus, a total of 10 preference scores per time point were formed by assigning values from 0 (= definitely not) to 4 (= definitely) to the answer choices and then adding them up. The value range of each preference score is 0 to 20, higher scores indicating higher preference for life-sustaining treatments (SPS) or higher preference for a particular treatment (TPS).

Data analysis

Descriptive statistics of baseline data were calculated for the acceptance of the instrument, global medical care goal-item, how would you feel-items, and for SPS and TPS. Missing data were not imputed. Cases were excluded for the respective SPS if an item of the scenario was not completed. The same applied to the TPS when items of the respective treatment scale were not completed as well as the global medical care goal-item.

In accordance with other psychometric evaluations [23–25] the acceptance of the instrument was assessed based on data from T0 by using completion rate and frequencies of missing data per item and of the whole instrument. The response options “not applicable” and “I do not wish to answer” were also counted as missing values, since these do not provide any content-related information about patients' preferences.

The internal consistency (Cronbach's α) of the preference score scales was calculated based on data from T0 as in Schwartz et al. 2004 [17] to test whether it was possible to create preference scores by scenario and treatment.

For concurrent validation as part of the criterion validation [26], the association between the global medical care goal-item and the SPS, both measured at baseline, was examined using Cramér's V as was the association between the how would you feel-items and the preference scores. Based on Schwartz et al. 2004 [17], it was expected that patients who preferred a longer life with possible health impairments would have higher preference scores than patients who preferred a shorter life without major health problems. By analogy, it was expected that patients who indicated on the how would you feel-item that living with the scenario health state would be acceptable would have a higher preference score than patients who indicated that life with the respective health state would be barely livable or not livable at all.

In addition, data from T0 and T2 were used to assess the responsiveness of the instrument to changes in preferences for life-sustaining treatments. For this, changes in preference scores from T0 to T2 were compared between and within study groups using non-parametric tests. On average, preference scores were expected to decrease in the IG, because preferences for life-sustaining treatments were expected to decrease. This assumption was made based on the results of systematic reviews indicating that ACP reduces preference for life-sustaining treatments [7, 27].

4.5 Results

Baseline characteristics showed no major differences between IG and CG. The mean age of the people participating in the validation study was 77 years (SD = 10.0), and 78.5% of participants were women; 36.3% had been hospitalized at least once in the last six months, and more than 80% had at least substantial limitations in activities of daily living (care grade 2 or higher; see Table 4-1).

On average, a Treat-Me-ACP interview lasted just over 17 minutes ($n = 73$; $SD = 9.0$). The shortest lasted 5 minutes, the longest 43 minutes. Only interviews that contained no more than five missing values were considered for the evaluation of the interview duration.

Tabelle 4-1: Baseline Patient Characteristics

	Intervention group (n = 40)	Control group (n = 40)	Total (N = 80)
Age in years			
Mean (SD)	75.98 (9.86)	78.47 (10.178)	77.22 (10.04)
Median [IQR]	77.50 [67.25-82.75]	79.50 [70.25-85.75]	79.00 [69.00-85.00]
Female	32 (80.0%)	30 (75.0%)	62 (77.5%)
Living alone	30 (75.0%)	29 (72.5%)	59 (73.8%)
Long-term care grade (n = 79)*			
None/1 (no or low limitations)	5 (12.5%)	9 (22.5%)	14 (17.7%)
2 (substantial limitations)	23 (57.5%)	25 (62.5%)	48 (60.8%)
3 (severe limitations)	11 (27.5%)	4 (10%)	15 (19.0%)
4/5 (very severe limitations)	0 (0.0%)	1 (2.5%)	1 (1.3%)
ACP document completed	32 (80%)	31 (77.5%)	63 (78.8%)
Comorbid diagnosis, lifetime prevalence			
Heart diseases	23 (57.5%)	19 (47.5%)	42 (52.5%)
Fractures	23 (57.5%)	24 (60.0%)	47 (58.8%)
Diabetes (n = 79)*	10 (25.0%)	10 (25.0%)	20 (25.3%)
Cancer	10 (25.0%)	12 (30%)	22 (27.5%)
Stroke (n = 78)*	6 (15.0%)	6 (15.0%)	12 (15.4%)
chronic obstructive pulmonary disease	8 (20.0%)	6 (15.0%)	14 (17.5%)
Parkinson's disease	1 (2.5%)	1 (2.5%)	2 (2.5%)
Dementia	0 (0.0%)	1 (0.0%)	1 (1.3%)
Hospitalization, last 6 months (n = 79)	13 (32.5%)	16 (40.0%)	29 (36.7%)

* Number of patients differs from n = 80 because of missing values.

4.5.1 Descriptive analysis

Global medical care goal

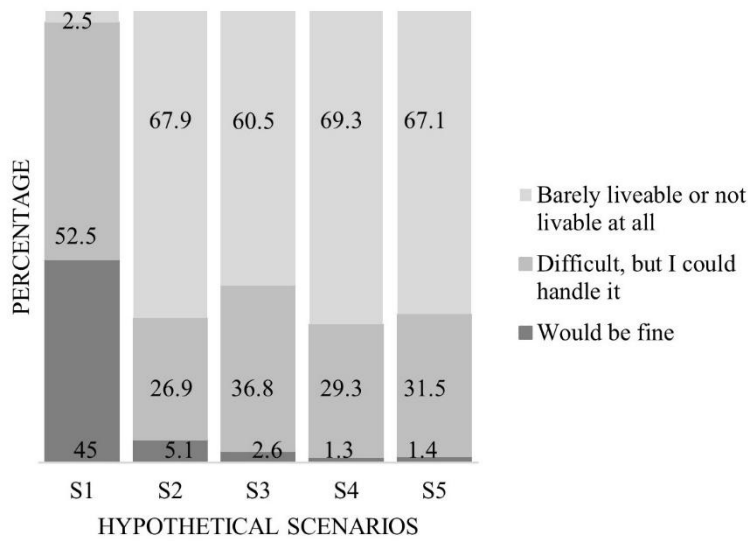
Of all patients, 76.6% stated at T0 that they would prefer care that is more likely to shorten their lives but causes no major health problems; the rest (23.4%) preferred to receive care aimed at living as long as possible, despite higher risk of major health problems.

How would you feel-items

The descriptive evaluation shows that 45% of patients would be content living with their current health status. Only 2.5% stated that life with this health status would be barely livable or not livable at all. The evaluation of the remaining items showed strong deviation from this result. More than 60% (60.5–69.3%) of participants considered life with health limitations as described in the scenarios to be barely livable or not livable at all. Only 1.3–5.1% stated that life with these limitations would be fine for them. Figure 4-2 shows the

descriptive results of the how would you feel-item for each scenario.

Figure 4-2: Response distribution of the *how would you feel*-items per scenario



Preference scores

Table 4-2 summarizes the descriptive statistics of the SPS and TPS across both study groups. The results demonstrate a wide range of SPS. S1 (current health status) had the highest preference scores, with a mean value of 11.58 (SD = 4.7), indicating that patients had stronger preferences for life-sustaining treatments in S1 than in S5 (incurable brain tumor), for which they stated the lowest preferences for medical care treatment (M = 3.9, SD = 4.9).

In comparison, all SPS show a tendency for less severe health limitations to lead to a higher preference for medical care treatment. Similar results were observed for the TPS. Mean TPS ranged from 9.9 (SD = 5.8) for TP1 (antibiotic treatment) to 1.7 (SD = 4.2) for TP5 (permanent artificial nutrition).

Table 4-2: Descriptive statistics of preference scores, internal consistency and concurrent validation parameters

Preference score scale	Preference scores			Internal consistency	Association of preference scores and global medical care goal	Association of scenario preference scores and <i>how would you feel</i> -items					
	Preference scores T0	Mean (SD) changes (T0-T2) in preference scores		Cronbach's α	n	Cramér's V	Significance	n	Cramér's V	Significance	
Scenario											
S1 – Current health status	69	11.6 (4.7)	-2.2 (3.4)	-1.2 (3.2)	0.718	66	0.596	0.136	69	0.805	0.103
S2 – Advanced dementia	69	5.6 (5.4)	-1.4 (4.5)	0.3 (5.4)	0.828	67	0.721	0.003	68	0.748	<0.001
S3 – Stroke with paralysis	70	6.1 (5.6)	-2.0 (4.0)	-1.2 (5.6)	0.838	68	0.636	0.051	68	0.889	<0.001
S4 – Stroke with six weeks coma	71	4.9 (5.6)	-1.5 (3.7)	-0.8 (4.9)	0.875	69	0.643	0.012	70	0.700	<0.001
S5 – Incurable brain tumor	66	3.9 (4.9)	-1.2 (3.2)	-1.9 (4.8)	0.838	64	0.534	0.195	65	0.836	<0.001
Treatment											
TP1 – Antibiotics	70	9.9 (5.8)	-1.5 (5.3)	-0.2 (4.6)	0.812	68	0.568	0.144			
TP2 – Resuscitation	69	5.0 (5.6)	-1.4 (2.1)	-1.4 (3.7)	0.854	67	0.694	0.002			
TP3 – Cholecystectomy	65	9.7 (6.1)	-2.9 (6.1)	-1.7 (5.1)	0.856	63	0.617	0.198			
TP4 – Temporary artificial nutrition	72	5.7 (6.4)	-3.3 (5.3)	-1.1 (5.9)	0.918	70	0.684	0.026			
TP5 – Permanent artificial nutrition	71	1.7 (4.2)	-0.2 (2.3)	0.7 (2.1)	0.962	69	0.696	<0.001			

Note: The minimum value of the preference scores is 0; the maximum value is 20. The higher the preference scores, the stronger the preference for life-sustaining treatments.

4.5.2 Validation

Acceptance of the instrument

The average completion rate of the instrument was 93.6% (SD = 0.2). The global medical care goal-item was completed by 96.2% of the patients. Across all how would you feel-items, the mean completion rate was 95.5% (SD = 3.4).

On average, 6.5% of the answers per item and two items per patient (SD = 5.3) were missing values. The number of missing values per item differed between scenarios. The more severe the health limitations described by a scenario, the higher the number of missing values. For example, items of S1 had on average 3.5% (SD = 3.3) missing values, for S5 the average of missing values was 11.3% (SD = 1.8). More information on the missing values can be found in Additional file B3.

Internal consistency

Cronbach's α shows high values for nine out of 10 scales (0.812–0.962; see Table 4-2). The scenario of current health status has a slightly lower but still sufficient value of 0.718. Based on Cronbach's α for the scenarios, we conclude that patients made consistent decisions for or against life-sustaining treatments within a scenario and thus that calculating the SPS as intended is possible. Cronbach's α of the treatment scales shows consistent decisions for or against a treatment across the different scenarios, and so the calculation of the TPS is also possible as intended.

Concurrent validation

For concurrent validation, the association between two criteria that were collected at almost the same time is analyzed [26]. Patients who indicated on the global medical care goal-item that they prefer a longer life with possible health limitations had consistently higher preference scores than patients who preferred a shorter life without health limitations (see Figure 4-3 and Figure 4-4). Cramér's V shows strong associations between the global medical care goal-item and all preference scores (see Table 4-2). The association is statistically significant for S2 – Dementia, S4 – Stroke with six weeks coma, TP2 (resuscitation), TP4 (temporary artificial nutrition), and TP5 (permanent artificial nutrition).

Figure 4-3: Association of the global medical and home care goal and the scenario preference scores

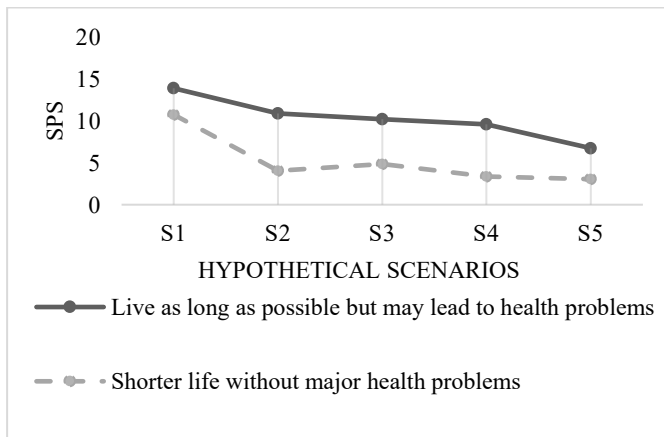
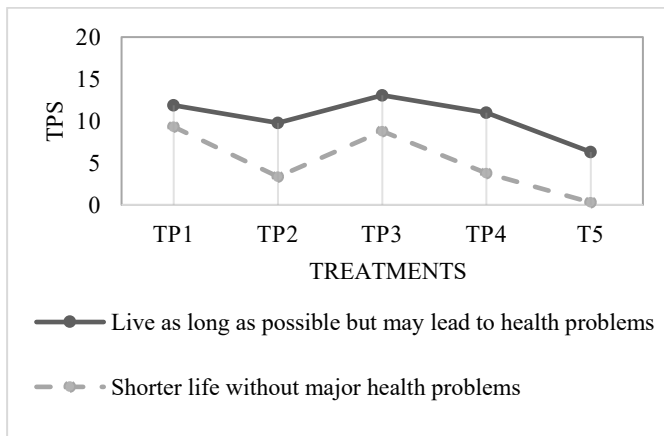
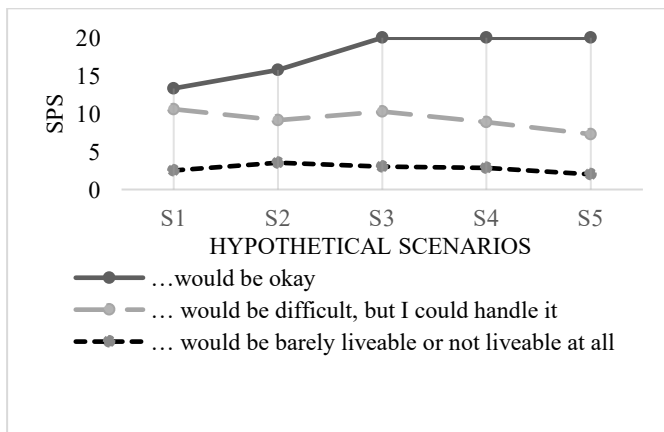


Figure 4-4: Association of the global medical and home care goal and the treatment preference scores



Patients who indicated that living with the respective health status would be acceptable had on average the highest preference scores. Patients who stated that such a life would be barely livable or not livable at all had on average the lowest preference scores for all scales (see Figure 4-5). Table 4-2 shows strong associations between the how would you feel-items and the SPS (statistically significant for S2 (advanced dementia), S3 (stroke with paralysis), S4 (stroke with six weeks coma), and S5 (incurable brain tumor)).

Figure 4-5: Association of the *how would you feel*-items and the scenario preference scores



Responsiveness of the instrument to changes in preferences for life-sustaining treatments

Baseline data show no statistically significant differences in preference scores between study groups. At T2, descriptive examination revealed a trend towards reduced preference scores for the IG across all scales, indicating a decreased preference for life-sustaining treatments in the IG (not statistically significant). In the CG, an increase in preference scores was observed for the scales S2 (advanced dementia) and S5 (permanent artificial nutrition) (see Table 4-2), indicating no consistent trend towards less invasive or life-sustaining treatments. Overall, with the exception of S5 (incurable brain tumor), the IG showed a greater reduction in preference scores than the CG when both groups showed a reduction.

4.6 Discussion

In this study, we aimed to develop and validate an instrument assessing dynamics of patient preferences during an ACP process (Treat-Me-ACP). Overall, the results show good psychometric characteristics regarding acceptance and feasibility. The average number of missing values varied widely within the scenarios and increased towards the end of the instrument. There are two possible explanations for this phenomenon. Firstly, scenarios were arranged in increasing intensity, as in the Life Support Preferences Questionnaires [15, 16] and the Emanuel Medical Directive [17]. This means that scenarios involving more severe health limitations were surveyed later in the interview. Preference scores tend to be lower for the more intensive scenarios, indicating a lower preference for life-sustaining measures. The intensity of the health limitations and stress caused by the scenarios presented to the patients later may be higher than in the earlier scenarios, thus increasing the stress on the patients and the probability of not answering the items. Secondly, we assume that patients' attention and concentration may decrease during the interview. The Treat-Me-ACP was the last part of the interview. In the study population, characterized by older age and care-dependency, patients' ability to concentrate may have been exhausted by the end of the interviews, causing increasing numbers of missing values [28–30]. Further research should evaluate whether the order of the scenarios has an impact on the completion rate and whether the increasing number of missing values is associated with a decreasing ability to concentrate during the survey.

Cronbach's α shows that calculating preference scores for this study population is possible by summation. In contrast to Schwartz et al. 2004 [17], no item had to be excluded from the calculation of preference scores, because we only asked about treatments that have a life-sustaining character and are not a general component of palliative care. Cronbach's α is

slightly lower for S1 (current health status) than for the other scenarios. This may be due to the fact that in contrast to the other scenarios, patients refer to their own health status when answering S₁ rather than to a given description of the health status. The high Cronbach's α may also be an indication that the scenarios and treatments can be adapted to the context of planned studies. For that, it must be ensured that (1) the scenarios differ in their accompanying health limitations and (2) the treatments differ in their intensity or invasiveness and have a life-sustaining effect (no palliative use).

Strong associations between the *how would you feel*-items and the SPS and the association between the global medical care goal-item and the two types of preference scores indicate satisfactory concurrent validity, suggesting that the scenarios represent the global medical care goal well. Our findings are consistent with those of Schwartz et al. 2004 [17]. A global medical care goal alone cannot adequately capture nuanced changes in wishes and preferences. Complex interventions require an in-depth understanding of their potential effects [31, 32]. The detailed portrayal of different health states and treatments by the Treat-Me-ACP thus supports appropriate evaluation of complex ACP interventions [31, 32].

As expected, the examination of responsiveness of the instrument to changes in preferences for life-sustaining treatments showed an average tendency for decreasing preferences for life-sustaining treatments across all scales for the IG during study follow-up. When the CG showed a reduction as well, the IG always showed a greater reduction in the preference scores than did the CG. Since 78.8% of participants had already completed ACP documents at T₀, it can be assumed that they had already addressed their wishes and preferences. Therefore, changes over time may have been smaller than in a study population that had been less engaged with.

Overall, the results of this validation study indicate that the Treat-Me-ACP is appropriate for generating additional outcome parameters for the evaluation of ACP interventions and the dynamics of medical treatment preferences in ACP. Possible use cases are summarized in Additional file B4.

Given that average preference scores tended to decrease for eight of 10 preference scores in the CG, the instrument itself may have an effect on patients' preferences. Study designs should therefore account for potential effects of scenarios on participants' reflections about their wishes and preferences.

4.6.1 Limitations

The study population is not representative for community-dwelling older persons in Germany. According to the German Federal Statistical Office, 60.2% of those in need of home care were female in 2019 [33], but in this study 78.5% of the patients are women. Women are therefore slightly overrepresented in this study. In addition, a large proportion of patients already had ACP documents at T0. Even though research on the prevalence of ACP documents in Germany is deficient, available data suggest that the prevalence of ACP documents in this study is well above average [34–37]. The study population therefore does not allow for generalization of the results. Furthermore, the study surveyed only a small sample. As a consequence, no statistically significant results were to be expected, and only trend statements about changes in patients' preferences can be made. The small sample also did not allow further analysis of the sequence of scenarios and their impacts. Thus, no statements can be made about how response behavior may have been influenced by the scenario sequencing.

Additionally, the sample used for this validation study was not randomly selected. This raises the possibility of a double selection bias that could result from the patients' decision to participate in the STADPLAN study and the selection by research assistants of participants for this sub-study based on patients' condition.

The Treat-Me-ACP has not been validated or correlated with a gold standard. This should be carried out in further research to determine the content validity of the instrument.

4.6.2 Conclusion

This study aimed to develop and validate the Treat-Me-ACP. The Treat-Me-ACP can be used to evaluate the dynamics of patients' medical treatment preferences in Advance Care Planning. In the international context, this study is one of few in recent years that has surveyed patient preferences in the ACP context based on scenarios. The instrument can be easily adapted for proxy assessment. During concurrent validation, we detected meaningful associations (1) between the scenario preference scores and the how would you feel-items and (2) between the preference scores and the global medical and home care goal.

4.7 List of abbreviations

ACP Advance Care Planning

CG control group

c-RCT cluster-randomized controlled trial

IG intervention group

S scenario

SPS scenario preference score

STADPLAN Study on Advance Care Planning in care-dependent community-dwelling older persons

TP treatment preference

TPS treatment preference scores

Treat-Me-ACP Treatment-Preference-Measure-Advance Care Planning

4.8 Declarations

Ethics approval and consent to participate

Ethical approval was obtained together with the main study from the ethics committees of the Medical Faculties of the Universities of the Martin Luther University Halle-Wittenberg (no. 2019-045), the Carl von Ossietzky University Oldenburg (no. 2019-024), and the University of Lübeck, Germany (no. 19-080) in a joint approval. The study was performed in accordance with the Declaration of Helsinki. Informed consent was obtained from all patients and their legal guardians.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

FH, SK, GM, and JKN designed the main study STADPLAN. FH was the responsible

coordinator of the STADPLAN study. JJ and JKN designed the health economic sub-study. JKN and JJ designed the statistical analysis plan for this secondary analysis of the health economics sub-study. AB, ÄK, and GM developed the intervention. JKN performed the randomisation. JKN performed the initial development steps. RS, KS, AB, ÄK, FH, GM and SK rated the translated instrument elements. JJ analyzed and interpreted the patient data. JJ and JKN drafted the manuscript. All authors read, made critical revisions and approved the final manuscript.

The corresponding author attests that all authors listed meet the authorship criteria and that no other authors meeting the criteria have been omitted.

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Additional Files

B1: Development and pre-test of the Treat-Me-ACP

Step 1: Development of a preliminary version

Methods

- Translation of the Life Support Preferences Questionnaires [1, 2] and the Emanuel Medical Directive [3] into German using the TRAPD-approach [4]
- Rating according to relevance, acceptability and appropriateness for the German healthcare context. Elements that received consensus were used
- Translation into patient friendly language by experts for easy language

Results:

- Instrument with nine scenarios:
 1. Current health status
 2. Advanced dementia
 3. Shortness of breath due to coronary heart diseases or chronic obstructive pulmonary disease
 4. Stroke with paralysis and speech disorder, with a certain probability that the condition will improve
 5. Stroke with paralysis and speech disorder, with no prospect of recovery
 6. Stroke with six weeks coma, with a certain probability that the condition will improve
 7. Stroke with six weeks coma, with no prospect of recovery
 8. Colorectal cancer with metastases in the liver, no pain
 9. Colorectal cancer with metastases in the liver, daily use of painkiller and one item to assess the patients' global medical care goal

Step 2: Assessment of comprehensibility, acceptance, and feasibility

Methods

- 1st round: ten cognitive interviews with probing questions with people without care need to optimize scenarios
- 2nd round: five cognitive interviews with individuals with care needs to test wording and understandability and assess acceptance and feasibility

Results

- Reduction to five scenarios where no ambiguity has occurred to reduce complexity and length of the instrument
- Replacement colorectal cancer by incurable brain tumor

Step 3: Final interview round with adapted instrument

Methods

- 13 interviews with probing questions to test for comprehensibility, acceptance, and feasibility again

Results

- The final instrument consists of five scenarios
 1. Current health status
 2. Advanced dementia
 3. Severe stroke with paralysis of one half of the body and speech disorder
 4. Severe stroke with six weeks coma
 5. Incurable brain tumor

and one item to assess the patients global medical care goal

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B2: English translation of the German Treat-Me-ACP

Note: This English version of the Treat-Me-ACP is a non-validated English version of the Treat-Me-ACP to help understand the analyses of the main manuscript. The validation study was conducted with the German version of the Treat-Me-ACP.

Treat-Me-ACP

Time: _____

Global medical care goal-item

When you think about your future, which care/treatment do you think is better?

- A care/treatment that allows you to live as long as possible. But this can cause health problems.
- A care/treatment where your life is shorter. But you do not have major health problems. You are not burdened by it.

Hypothetical scenarios

In the following, I describe various health conditions for you. Please answer the questions. And try to put yourself in these situations.

Hypothetical scenario 1: Current health status

S1 – *How would you feel-item*: You are in your current state of health. Your state of health is how you feel today. Imagine feeling that way for the rest of your life. What would that be like for you?

- That kind of life would be all right for me.
- That kind of life would be difficult. But I could handle it.
- That kind of life would be barely livable or not livable at all.

S1.TP1: Imagine that you suddenly get a serious infection, such as pneumonia. If you take antibiotics, the infection can be cured. If you do not take antibiotics, you could get life-threatening complications or die. Would you want to take antibiotics?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S1.TP2: Imagine your heart suddenly stopped beating. Would you like to be resuscitated?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S1.TP3: Imagine you have an inflammation of the gallbladder. Surgical removal of the gallbladder can prevent life-threatening complications. This type of surgery is now considered routine, and the loss of the gallbladder can be tolerated without discomfort.

Would you like to have your gallbladder removed?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S1.TP4: Imagine you could no longer eat and drink by yourself. Would you wishant to be fed artificially for a foreseeable period of time?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S1.TP5: Imagine you could no longer eat and drink by yourself. Would you want to be fed artificially for the rest of your life?

- Definitely not
- Unlikely
- Neither likely nor unlikely

- Likely
- Definitely
- Not applicable
- I do not want to answer

Hypothetical scenario 2: Advanced dementia

Imagine you have very advanced dementia. This means

- You cannot think clearly. You are confused and often do not recognize your family members.
- You do not seem interested in what is going on in the world around you.
- You are not in pain. You are physically fine.
- There is no cure.

S2 – *How would you feel*-item: How would you feel if you spent the rest of your life in this state of health?

- That kind of life would be all right for me.
- That kind of life would be difficult. But I could handle it.
- That kind of life would be barely livable or not livable at all.

S2.TP1: Imagine that you suddenly get a serious infection, such as pneumonia. If you take antibiotics, the infection can be cured. If you do not take antibiotics, you could get life-threatening complications or die. Would you want to take antibiotics?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S2.TP2: Imagine your heart suddenly stopped beating. Would you like to be resuscitated?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S2.TP3: Imagine you have an inflammation of the gallbladder. Surgical removal of the gallbladder can prevent life-threatening complications. This type of surgery is now considered routine, and the loss of the gallbladder can be tolerated without discomfort. Would you like to have your gallbladder removed?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S2.TP4: Imagine you could no longer eat and drink by yourself. Would you wishant to be fed artificially for a foreseeable period of time?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S2.TP5: Imagine you could no longer eat and drink by yourself. Would you want to be fed artificially for the rest of your life?

- Definitely not
- Unlikely

- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

Hypothetical scenario 3: Stroke with paralysis

Imagine you had a stroke.

- As a result, one side of your body is paralyzed. That is, one arm and one leg.
- You have difficulty expressing yourself clearly.
- You need help with all kinds of activities.

You have psychological damage from the stroke. Your doctor says the mental damage will not go away. Physically, however, you will recover from the event.

S3 – *How would you feel*-item: How would you feel if you spent the rest of your life in this state of health?

- That kind of life would be all right for me.
- That kind of life would be difficult. But I could handle it.
- That kind of life would be barely livable or not livable at all.

S3.TP1: Imagine that you suddenly get a serious infection, such as pneumonia. If you take antibiotics, the infection can be cured. If you do not take antibiotics, you could get life-threatening complications or die. Would you want to take antibiotics?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S3.TP2: Imagine your heart suddenly stopped beating. Would you like to be resuscitated?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S3.TP3: Imagine you have an inflammation of the gallbladder. Surgical removal of the gallbladder can prevent life-threatening complications. This type of surgery is now considered routine, and the loss of the gallbladder can be tolerated without discomfort. Would you like to have your gallbladder removed?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely

- Not applicable
- I do not want to answer

S3.TP4: Imagine you could no longer eat and drink by yourself. Would you wishant to be fed artificially for a foreseeable period of time?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S3.TP5: Imagine you could no longer eat and drink by yourself. Would you want to be fed artificially for the rest of your life?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

Hypothetical scenario 4: Stroke with six weeks coma

Imagine you had a stroke.

- You were in a coma for six weeks.
- You need help with all activities.
- You can live in this condition for several years.

You have mental damage from the stroke. Your doctor says the mental damage will go away.

Physically, however, you will not recover from the event.

S4 – *How would you feel*-item: How would you feel if you spent the rest of your life in this state of health?

- That kind of life would be all right for me.
- That kind of life would be difficult. But I could handle it.

- That kind of life would be barely livable or not livable at all.

S4.TP1: Imagine that you suddenly get a serious infection, such as pneumonia. If you take antibiotics, the infection can be cured. If you do not take antibiotics, you could get life-threatening complications or die. Would you want to take antibiotics?

- Definitely not
 Unlikely
 Neither likely nor unlikely
 Likely
 Definitely
 Not applicable
 I do not want to answer

S4.TP2: Imagine your heart suddenly stopped beating. Would you like to be resuscitated?

- Definitely not
 Unlikely
 Neither likely nor unlikely
 Likely
 Definitely
 Not applicable
 I do not want to answer

S4.TP3: Imagine you have an inflammation of the gallbladder. Surgical removal of the gallbladder can prevent life-threatening complications. This type of surgery is now considered routine, and the loss of the gallbladder can be tolerated without discomfort. Would you like to have your gallbladder removed?

- Definitely not
 Unlikely
 Neither likely nor unlikely
 Likely
 Definitely
 Not applicable
 I do not want to answer

S4.TP4: Imagine you could no longer eat and drink by yourself. Would you wishant to be fed artificially for a foreseeable period of time?

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- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S4.TP5: Imagine you could no longer eat and drink by yourself. Would you want to be fed artificially for the rest of your life?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

Hypothetical scenario 5: Incurable brain tumor

Imagine you have a malignant brain tumor.

- You feel tired and weak.
- You spend most of your time in bed.
- Your mental health is affected.
- You have no pain.

Your doctor says the cancer is incurable. He estimates that you have six months to live.

S5 – *How would you feel*-item: How would you feel if you spent the rest of your life in this state of health?

- That kind of life would be all right for me.
- That kind of life would be difficult. But I could handle it.
- That kind of life would be barely livable or not livable at all.

S5.TP1: Imagine that you suddenly get a serious infection, such as pneumonia. If you take antibiotics, the infection can be cured. If you do not take antibiotics, you could get life-threatening complications or die. Would you want to take antibiotics?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S5.TP2: Imagine your heart suddenly stopped beating. Would you like to be resuscitated?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S5.TP3: Imagine you have an inflammation of the gallbladder. Surgical removal of the gallbladder can prevent life-threatening complications. This type of surgery is now considered routine, and the loss of the gallbladder can be tolerated without discomfort.

Would you like to have your gallbladder removed?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S5.TP4: Imagine you could no longer eat and drink by yourself. Would you wishant to be fed artificially for a foreseeable period of time?

- Definitely not
- Unlikely
- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

S5.TP5: Imagine you could no longer eat and drink by yourself. Would you want to be fed artificially for the rest of your life?

- Definitely not
- Unlikely

Measuring Patients' Medical Treatment Preferences in Advance Care Planning – Additional Files

- Neither likely nor unlikely
- Likely
- Definitely
- Not applicable
- I do not want to answer

Time: _____

B3: Missing values

Table 4-A1: Missing values at baseline

Item	Missing values (%)	SD
Global medical and home care goal	3.8	0.4
S1 – Current health status	M: 3.5; MD: 2.5	3.0
S1 – <i>How would you feel</i> -item	0.0	0.6
S1.TP1 – Antibiotics	1.3	1.1
S1.TP2 – Resuscitation	6.3	1.7
S1.TP3 – Cholecystectomy	8.8	1.2
S1.TP4 – Temporary artificial nutrition	2.5	1.7
S1.TP5 – Permanent artificial nutrition	2.5	1.1
S2 – Advanced dementia	M: 5.2; MD: 4	3.0
S2 – <i>How would you feel</i>-item	2.5	0.6
S2.TP1 – Antibiotics	2.5	1.7
S2.TP2 – Resuscitation	7.5	1.3
S2.TP3 – Cholecystectomy	10.0	1.7
S2.TP4 – Temporary artificial nutrition	3.8	1.5
S2.TP5 – Permanent artificial nutrition	5.0	0.9
S3 – Stroke with paralysis	M: 5.6; MD: 5.0	1.7
S3 – <i>How would you feel</i>-item	5.0	0.6
S3.TP1 – Antibiotics	5.0	1.6
S3.TP2 – Resuscitation	6.3	1.4
S3.TP3 – Cholecystectomy	8.8	1.6
S3.TP4 – Temporary artificial nutrition	3.8	1.5
S3.TP5 – Permanent artificial nutrition	5.0	0.9
S4 – Stroke with six weeks coma	M: 7.1; MD: 6.9	1.0
S4 – <i>How would you feel</i> -item	6.3	0.5
S4.TP1 – Antibiotics	7.5	1.6
S4.TP2 – Resuscitation	7.5	1.3
S4.TP3 – Cholecystectomy	8.8	1.5
S4.TP4 – Temporary artificial nutrition d	6.3	1.4
S4.TP5 – Permanent artificial nutrition	6.3	0.8
S5 – Incurable brain tumor	M: 11.3; MD: 11.3	1.8
S5 – <i>How would you feel</i>-item	8.8	0.5
S5.TP1 – Antibiotics	12.5	1.6
S5.TP2 – Resuscitation	11.3	1.2
S5.TP3 – Cholecystectomy	13.8	1.4
S5.TP4 – Temporary artificial nutrition	10.0	1.4
S5.TP5 – Permanent artificial nutrition	11.3	0.8

B4: Use cases of the Treat-Me-ACP

Note: This document shows different examples of applications and interpretations of the Treat-Me-ACP instrument. These are some of the things we have thought about when developing the tool. To show the practical application of the Treat-Me-ACP, the mean value of the study population is used, but interpreted as belonging to one patient.

Cross-sectional survey

Make trend statements about whether life-sustaining treatments are more preferred or whether non-life-sustaining measures are more preferred

The *global medical goal*-item can be used to indicate a patient's (non)preference for life-sustaining treatment. This item consists of a dichotomous question in which the patient indicates whether he or she generally prefers care or treatment that will allow him or her to live as long as possible but may lead to health problems or whether he or she prefers a shorter life with major health problems.

The *global medical care goal*-item provides an opportunity for an initial assessment of preferences. In the next step, the preference scores can be used to check whether the global goal is reflected in the preference scores. If there is a preference for a shorter life with fewer health problems, the preference scores should be lower than if there is a preference for a longer life with possible health limitations.

Identify current preferences for different health limitations (scenarios) and different invasive treatments (treatments)

The preference scores allow for a more detailed differentiation of preferences for different health states and treatments.

Figure 4-A1 shows that the patient has the strongest preferences for life-sustaining interventions in the current state of health (scenario 1). Preferences for life-sustaining interventions are low for the remaining health states queried.

Figure 4-A1: Scenario preference scores of the patient

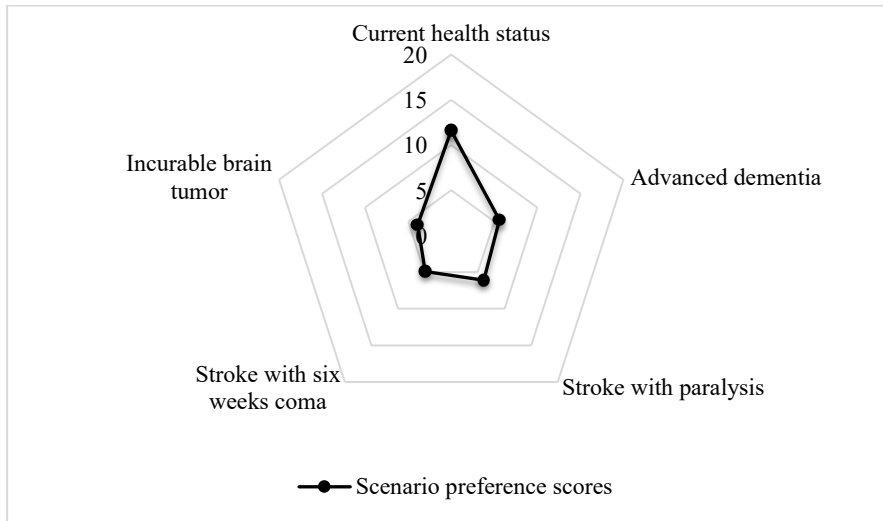
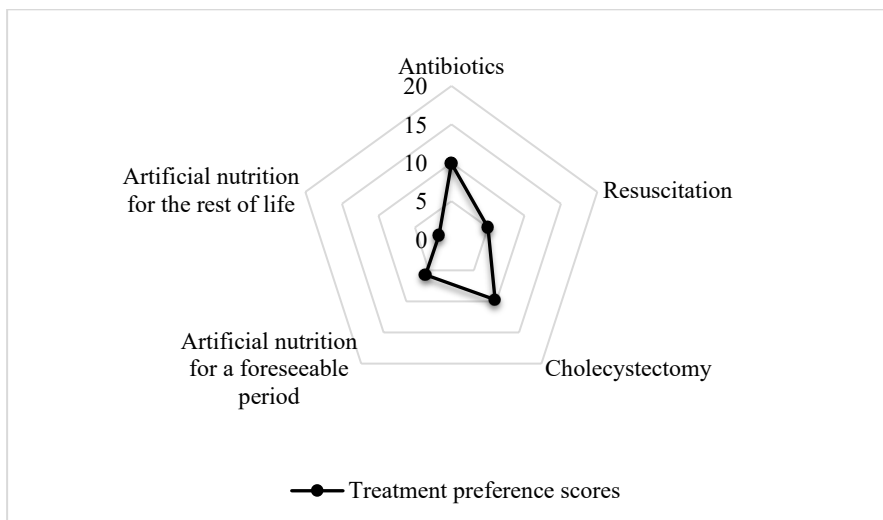


Figure 4-A2 shows that the patient has the strongest preferences for treatments that are likely to be associated with few long-term health limitations (antibiotics and cholecystectomy). Treatments that are more invasive or associated with more severe limitations are less preferred or not preferred at all.

Figure 4-A2: Treatment preference scores of the patient



Longitudinal survey

Trend of preferences over time, in order to be able to make statements about the stability of preferences

Figures 4-A3 and 4-A4 show the patient's preference scores at two points in time. By plotting the two time points on a radar chart, the changes in preferences can be seen. This allows a statement to be made about the stability of the preferences. Additional time points can be used to determine the stability of preferences over time.

In the example shown, the curve for the second time point lies continuously within the curve for the first time point. This means that the preference for life-sustaining treatment has decreased slightly.

Figure 4-A3: Scenario preference scores of the patient; comparison of two points in time

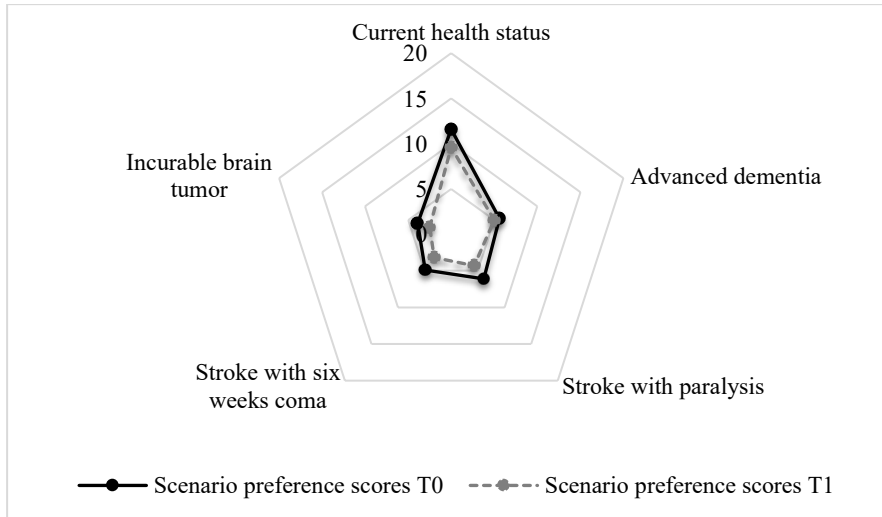
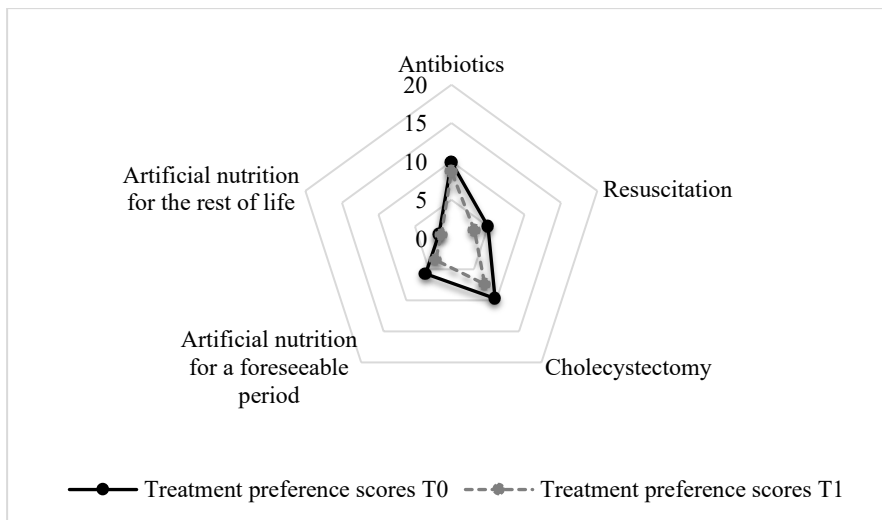


Figure 4-A4: Treatment preference scores of the patient; comparison of two points in time



Statements about changes in preferences after an intervention to analyse the effectiveness

By comparing preference scores at different time points, as shown in Figures 4-A3 and 4-A4, it is possible to make statements about changes in preference scores following an advance care planning intervention. The Treat-Me-ACP is therefore an instrument that can be used as a complementary tool to evaluate effectiveness. To assess effectiveness, the preference scores at different time points must be analyzed using appropriate statistical methods, which may differ depending on the study design.

5 Discussion

In this dissertation a scoping review was conducted that examined whether current ACP research aligns with the concept's foundational definition, which is to enable all people, regardless of age or health status, to express their wishes and preferences for medical and nursing care (Rietjens et al. 2017). The target groups of ACP interventions that have been evaluated or published in study protocols, the care settings in which the ACP interventions are delivered, and how they have been developed were identified. The results indicate that ACP interventions are mainly available to older and chronically/seriously ill people and that there are only a few evaluated interventions for younger/healthier target groups. Existing research to date therefore does not fulfill the ACP definition by Rietjens et al. 2017.

Based on this result, a low-threshold and low-cost conversation game titled *Hey du*, which has already been evaluated in several studies in the United States, was systematically translated into German and the acceptability of this intervention was tested in two convenience samples. The results of the acceptance evaluation showed that the participants had no concerns about using *Hey du* and that it can be an appropriate tool for people to begin to reflect on and formulate their own wishes and preferences as well as to learn to communicate these to other people (Jaschke et al. 2025). As there were no acceptance problems with the use of *Hey du* (Jaschke et al. 2025), there is currently no obvious reason why *Hey du* should not have a positive impact on ACP engagement, as in the United States (Radhakrishnan et al. 2019; van Scoy et al. 2016; van Scoy et al. 2017; van Scoy et al. 2022b), even though the study conducted is not an effectiveness evaluation.

To evaluate the effectiveness of ACP interventions such as *Hey du* (Jaschke et al. 2025), which are aimed at broad public effectiveness, outcomes are needed that do not depend on the occurrence of critical care situations (e.g. death or incapacity); the reason for this is that the healthier and younger the population is, the less likely it is critical care situations will occur. Thus, long-term outcomes such as hospitalization, the frequency of use of life-sustaining measures, and length of stay are not suitable for evaluating ACP interventions when the study population tends to be younger/healthier. Instead, early outcomes are needed that do not depend on the occurrence of critical care situations, but rather on, for example, the individual's process of change. For this reason, the Treat-Me-ACP was developed and validated as part of a secondary analysis of a cluster randomized controlled trial. The results of the validation study demonstrated good psychometric characteristics and indicated that the Treat-Me-ACP is an appropriate outcome instrument for the evaluation of ACP

interventions (Jaschke et al. 2024).

This work aligns well with recent years' ACP research initiatives, which have focused on expanding ACP's target groups. For example, doctors are asked to ask all their patients if they have chosen a health proxy and, if so, what they have discussed with them (McMahan et al. 2024). Recommendations for policy initiatives and research to strengthen ACP for dementia patients have been drawn up (Nakanishi et al. 2024), and many studies have focused on ACP in minority or underserved populations (e.g., Yamarik et al. 2024; Li et al. 2024; Nouri et al. 2023; Mindo-Panusic et al. 2023; van Scoy et al. 2022a). These populations have not been well represented thus far (Hickman et al. 2023). *Hey du* offers the opportunity to introduce a low-threshold, cost-effective initial ACP intervention systematically in the German-speaking environment that can reach population groups beyond nursing home residents and integration assistance facilities (Jaschke et al. 2025).

Another aspect of ACP research that is currently being discussed is the still evolving definition and conceptualization of ACP (Hickman et al. 2023), into which *Hey du* continues to fit. In the context of care planning, ACP recognizes that people's wishes and preferences can change repeatedly throughout their lives (Hickman et al. 2023). These depend on the individual's own definition of quality of life, their readiness, and their understanding of their state of health and any existing illnesses, as well as being influenced by family members, loved ones, care providers and current policies. Those who wish to do so can and should communicate and document their wishes and preferences at an early stage in life (Hickman et al. 2023). It is conceivable that concepts will be developed to make *Hey du* accessible to those who wish to have their first experience of ACP at an early stage in life.

A third area of ACP research that is subject to change are the assessed outcomes. Initially, a frequently used outcome in ACP research was the frequency of ADs because it was easy to measure (McMahan et al. 2024). Successful ACP is now perceived as a process involving various change processes (McMahan et al. 2024) including 1) becoming aware of one's own wishes and preferences; 2) communicating these wishes and preferences, and 3) documenting them when appropriate (Sudore und Fried 2010; Sinuff et al. 2015). This means that additional early outcomes are needed to assess these change processes. The Treat-Me-ACP is designed to address the evolving demands placed on instruments for the evaluation of ACP interventions. This instrument assesses the dynamics of patient preference during an ACP process and enables interventions to be evaluated even when long-term outcomes cannot be observed (Jaschke et al. 2024).

5.1 Contributions and implications

The scoping review performed in section 2 revealed that current ACP research does not align with the foundational definition of the ACP concept, namely, that all people, regardless of their age or health status, should be enabled to express their wishes and preferences for medical and nursing care. Substantial gaps exist in the target groups addressed by ACP interventions and the geographical distribution of ACP research. As ACP interventions primarily target older individuals with existing health issues in high-income countries, the question of how far the research findings to date can be applied to other cultures and target groups should be raised. In addition, there is a predominance of institutional settings that limit access to ACP for individuals who are not already engaged in the healthcare system.

Future researchers can use the scoping review to gain an understanding of ACP interventions that have already been evaluated. This information can be used to inform further research or to identify target groups and care settings for which little or no research has been conducted to date. This approach has the potential to make research resources more effective by building on existing interventions and results.

To counteract the focus on older people who are already ill, the acceptability and comprehensibility of an ACP intervention (*Hey du*) was tested in section 3. The results of the acceptance study indicate that *Hey du* has the potential to be an effective and affordable ACP intervention with a low threshold (Jaschke et al. 2025). Studies from the United States indicate that *Hey du* can positively impact the ACP behavior of the players (Radhakrishnan et al. 2019; van Scoy et al. 2016; van Scoy et al. 2017; van Scoy et al. 2022b). Further research is needed to assess the impact of *Hey du* on ACP behavior in Germany, particularly among different age groups and socioeconomic backgrounds. *Hey du* could also be used in a therapeutic context by nurses, occupational therapists, speech therapists and physical therapists who deal with end-of-life issues and death in their daily work. Among this target group, the impact of *Hey du* on therapists' confidence in conducting ACP discussions with patients could be evaluated. *Hey du* could also be used in caring communities (Koordinationsstelle des Hospiz- und Palliativnetzwerkes n.d.; Meesters et al. 2024) as it is low-threshold and inexpensive to implement.

Additionally, the Treat-Me-ACP tool was developed and validated to assess the dynamics of study participants' preferences during an ACP process (Jaschke et al. 2024). This means that there is now a German instrument that can be used to assess participants' preferences in ACP interventions and trace changes in them. The Treat-Me-ACP complements existing

evaluation instruments as it is an early outcome instrument: Early outcome instruments can be used to evaluate the effectiveness of ACP interventions when long-term outcomes, such as length of stay and hospitalizations, cannot be observed (Jaschke et al. 2024).

5.2 Conclusion

This dissertation highlights that previous ACP interventions have primarily targeted older people and those who are already (seriously) ill. This means that previous ACP research does not align with the definition of ACP, which states that everyone, regardless of their health or age, should be enabled to communicate their medical and care preferences before death. *Hey du*, a conversation game that has been tested for acceptability and comprehensibility, is an ACP intervention intended to better fit this definition. By piloting *Hey du* an ACP intervention was tested that is also aimed at younger and healthier individuals, and thus better aligns with the concepts' definition.

Interventions aimed at younger and healthier individuals require outcome instruments that measure early outcomes as critical care situations such as an inability to give consent or a deterioration in health occur less frequently – or not at all – during the observation periods of studies, as compared to those of older individuals or individuals who are already (seriously) ill. The Treat-Me-ACP can be used to assess the dynamics of participants' preferences during the ACP process, thus facilitating the evaluation of such interventions.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author used DeepL (DeepL SE n.d.a) and DeepL write (DeepL SE n.d.b) to improve the linguistic quality of the manuscript before proofreading. After using this tool, the author reviewed and edited the content as needed and takes full responsibility for the content of the manuscript.

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