Shared Decision Making in Advanced Care Planning

A qualitative evidence synthesis on patient reported barriers and facilitators of shared decision making in the setting of advanced care planning

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Abstract

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Objective: The aim of this study was to obtain an overview of patient reported barriers and facilitators to participation in the shared decision making (SDM) process, especially in the setting of advanced care planning (ACP). We aimed to examine differences and similarities between barriers and facilitators in the setting of ACP compared to SDM in other decisional settings. Identifying these factors might contribute to overcoming the challenges that patients face in the ACP process.
Methodology: A qualitative evidence synthesis was conducted in which five databases were consulted. The search strategy was composed of MeSH terms and free-text words consisting of synonyms and derivatives of relevant terms such as “shared decision-making”, “patient”, and “barriers/facilitators”. We opted for an in-depth synthesis of selected studies, applying a mixed purposeful sampling strategy.
Results: From the analysis of the 10 included studies, we withhold four important themes regarding patient reported SDM barriers and facilitators in the setting of advanced care planning. These include the medical encounter, the readiness of the patient, the role of social (family) support and the purpose of life. The last two reported themes are most typical for shared decision making in the advanced care planning setting. The role of the family plays a much larger role, and how a patient approaches life and death becomes an additional topic. Additionally, the readiness of the patients plays a significant role. Readiness is essential for ACP to be conducted.
Conclusion: Further research is needed to map out tools to overcome the identified barriers, emphasize the reported facilitators, and acknowledge the role of family and spirituality in the process.

Foreword

By this writing I would like to thank my promotors, Prof. Mieke Vermandere who provided guidance and gave me the opportunity to be part of this valuable research subject, to Prof. Bert Aertgeerts who provided support, and all who were involved in the process.
Special thanks to my co-promotor, Dr. Lien Mertens, for the many inspiring Zoom meetings, the feedback and the pleasant cooperation.
I am grateful to have been part of this challenging, interesting and intensive research process.
It was delightful to discover that some findings of this study, corresponded to my experience and interaction with some patients in general practice, which made the literature come alive and act as a great driving force.

"The more you know, the more you know you do not know." - Aristotle

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1 Introduction

As this thesis is a part of a larger doctoral research component focusing on patient reported barriers and facilitators of shared decision making (SDM), the focus of this paper will be on patient reported barriers and facilitators particularly in the setting of advanced care planning (ACP).

1.1 Shared Decision Making

Shared decision making (SDM) is a process that supports patients in making medical choices based on recent evidence and this in collaboration with the healthcare providers, taking into account each patient's background such as the current situation, choice preferences and norms and values of the individual patient [1, 2]. As such it concerns the process which involves communication between a healthcare provider and a patient in a collaborative manner [3-5]. By helping patients to better understand treatment options and by giving them voice, SDM helps to modify the power dynamics of decision making and give a more central role to the patient [3-5]. In addition, SDM has been referred to as a model of medical care adapted to the patient's situation and his personal needs [6, 7]. Although SDM is a concept that is taking a more prominent role in literature and daily practice over the last decades, it is not implemented routinely in today's healthcare [8-10].

Currently, a universal and unambiguous definition for this concept is lacking [3, 11], and a uniform insight or a model of how it can be implied and achieved is lacking [3, 9]. This implies the importance of having insight into relevant factors concerning this topic.

In a recent critical discourse analysis commonly used definitions of shared decision making through the years were examined with the aim of clarifying the state of social reality constructed by language [11]. Striking are the results suggesting that patients are more often described as occupying a passive role in the process, where the healthcare provider takes on a communicating active role [11]. This seems to oppose the aim of shared decision making in clinical practice. Furthermore, the analysis of definitions suggests that SDM is a 'gift' that the health care provider has the power to offer. Patients are constructed as a source of information-input to the SDM process rather than playing an active role in it. They are described as not always considered to be able to deliberate themselves [11], contradicting the commonly known concept of SDM. This shows that even in the definitions of SDM the old view of medicine where the patient listens, and the healthcare provider speaks is still not totally abandoned [11]. This analysis of definitions may reflect a big part of the current healthcare system. Healthcare providers are limited by their communication techniques [12], their own attitudes towards SDM [13], the available time during a consultation [9, 14] and in the use of decision aids [15] [11]. On the other hand patients are not aware that their opinions matter and they are allowed to participate into shared decision making [10] [11].

The goal of SDM is to involve and help patients taking medical decisions by empowering them and by providing information in a way that makes them able to do so, according to their personal preferences [2, 7, 16, 17]. To achieve this healthcare providers need to be more aware of their role and patients need to be stimulated to participate in the process of shared decision making. It implies a further shift in the roles, power dynamics and interaction between health care provider and patient which is challenging to reach [3, 18], coming from an initial paternalistic model changing to a model where the patient plays a more significant/central role and decision making takes place between patient and healthcare giver as partners [19]. Although studies have shown that most healthcare providers prefer a SDM approach, decisions are still frequently made by the healthcare providers themselves [19]. However, it has been shown that involving a patient in treatment decisions results in a decision consistent and most close to their own personal preferences this because of less decisional regret and a better compliance [19, 20].

Literature shows that there is a misconception among healthcare providers concerning the role of patients in shared decision making, stating that some patients don't want to participate in shared decision making [2, 6, 11, 17, 21, 22]. It rather seems that some patients simply can't participate [2]. It looks that health care providers are more likely to apply SDM when the patient expresses a desire to be involved and when the patient is perceived by the health care provider as competent to do so [19, 23]. This implies that SDM is less conducted when caregivers perceive patients as not interested or not capable to share decisions for example because of the lack of communication skills or having less awareness about their (medical) condition because of a lack of medical knowledge [19, 24].
The desire to take part in SDM depends on the patient's role preferences, which is a variable and complex element. Studies have shown that the role preferences are influenced by patient's demography, previous experiences with shared decision making, knowledge and attitude, the existing relationship with the health care provider, overall health, received diagnosis, and so on [25]. It is known that particular patient groups tend to be more involved in the process of SDM than others [2, 26]. Contributing factors are the patient's gender favoring women, the patient's education level and other aspects as patient's income, race, age [2, 26], the socioeconomical status [27, 28], and health literacy [29].
Additionally, the willingness and ability of one particular patient may vary over time [25], as other variable and non-variable aspects play part (eg, relationship between healthcare provider and patient, the provided time, emotional aspects,...) [30]. There is currently still place to improve the application of SDM in clinical practice to better overhear patient differences and preferences [31, 32] and cope with the interpersonal behavior [33]. Nor it is not yet common to educate medical students in applying SDM [31]. The most vulnerable patients are at a disadvantage [34]. Having insight in the contributing factors of SDM can help to improve the use of SDM models and the applicability, taking the misconceptions about SDM into account.

Over the last decades research has been conducted about barriers and facilitators of shared decision making [2, 9, 35], but recent literature about patient reported barriers and facilitators is lacking [2]. Existing research is focusing mainly on certain patient groups in certain health settings but comparative research and analysis of these groups among each other is missing.

1.2 Advanced Care Planning

The last thirty years the topic of advanced care planning became an important research subject [36]. The aim of ACP is to grant care near the end of life, according to the patient's wishes, in a moment that the decisional capacity might lack [36-40]. It's a way to make plans about future health care [38]. This goal can be achieved by helping, as a health care professional, the patient to understand their wishes and support the patient to share their goals, values and preferences in case of potential future medical care decisions [36, 38]. Furthermore, this process consists of documenting these wishes [36, 40].
Since ACP doesn't focus on 'in the moment' decision making, it encourages all adults to participate regardless of their health status [36]. However, this looks promising the evidence that ACP influence medical decision making at the end-of-life is lean [36, 41]. In literature eight steps have been identified on which the success of ACP depends [36]. Where it is important that the patient can express his wishes taking into consideration future hypothetical scenarios and that a surrogate is involved and available to represent the patient's initial preferences [36].
It should be noted that patient's preferences are not static and can be influenced by dynamic factors like cognitive and physical function, age, financial resources, family preferences, culture, advice of the clinician, and the burden of the disease and needed care of the patient [36]. This makes applying ACP in practice challenging.

1.3 Study aim

The goal of the doctoral study, where this thesis relates to, is to explore patient's perspective of shared decision making. The doctoral study aims to analyze and compare patient reported barriers and

facilitators between different patient groups and try to gain more insight in preferences and needs of diverse patients in the context of SDM, and especially the most vulnerable ones. The obtained insights might help to acquire better implementation of SDM in daily practice, to involve diverse patients in the process of SDM and to contribute to the knowledge concerning the development of patient decision aids and serve educational purposes towards medical students and professionals.

In this qualitative evidence synthesis, we aim to point out patient-reported barriers and facilitators to participation in the SDM process, especially of advanced care planning (ACP). Identifying these factors might contribute to overcome the challenges that patients are facing in the ACP process, which are mentioned in the previous topic, and support the development of new guidelines and educational materials to guide the process.

1.4 Research questions

Research questions for this study include:
-What are most frequently reported barriers and facilitators to participation in shared decision making by patients in the setting of advanced care planning?
-What are the differences and similarities between barriers and facilitators in the setting of ACP compared to SDM in other decisional settings?

2 Method

2.1 Study design

The main goal of this review is to examinate facilitators and barriers from patients' perspective in the context of shared decision making and ACP. To attempt to fill the related knowledge gap, a qualitative evidence synthesis was conducted according to the PRISMA Checklist for systematic reviews [42] [43]. In PROSPERO the research protocol was registered, with ID number CRD42022360313. From this broader approach we could distract studies related to ACP specifically.

2.2 Search strategy

This review includes articles from 2012 onwards with language restriction limited to Dutch and English, without restriction concerning the country of publication.
To include relevant studies five databases among which MEDLINE via Pubmed, CINAHL, EMBASE, Scopus and Web of Science were consulted.
The search strategy was made up of MeSH terms and free-text words consisting of synonyms and derivatives of relevant terms such as "Shared decision-making", "Patient", "barriers/facilitators", as presented in appendix 1. An expert librarian was consulted to assist in the process of the search building.

2.3 Selection criteria

Inclusion criteria consist of patients from the age of 18 year and above. The term 'patient' is defined as anyone who is a potential healthcare user, regardless of the setting (primary, secondary or tertiary; inpatient or outpatient), the health condition or the population where the patient belong to. In this review only empirical literature was included, consisting of quantitative or qualitative or mixed methods study designs, which imply the exclusion of any other recourses such as letters, case studies, study protocols, grey literature, dissertations, and so on. The exclusion criteria consist of patients younger than 18 years, patients with cognitive impairments or a (temporary) lack of mental capacity, such as unconscious/comatose patients, prohibiting their participation in shared decision making, and simulation patients. The exclusion also includes patients facing unexpected life-threatening emergency needing immediate lifesaving care.

Specified inclusion and exclusion criteria from point of interest:
Studies based on direct reported barriers and facilitators by patients were included. In case of surrogate or substitute decision making the study was not included. As earlier mentioned, studies who include patients younger than 18 years were excluded. Additionally, in case adults are being questioned about the experienced shared decision-making process as a child (<18 years) the study was also excluded. Patient participation preference studies were also excluded, as the focus lie on elements that influence the actual involvement and not the preferred involvement. The focus of this study is on the shared decision making between a doctor and a patient, so studies who include interactions with other healthcare givers (dentists, nurses, physiotherapists, ...) were excluded. Studies who focus on participation in care, in general were excluded. In case of patient participation in advanced care planning and end-of-life discussions the studies were included. Studies who focus mainly on informed consent and informed decision-making were not included. When an intervention (patient decision aids, training programs, ...) is being examined in the decision-making process the study was excluded. Studies describing researcher reported associations were not included. Studies who report patient related characteristics, were only included if the characteristics were patient reported. In case the patient related characteristics are related with participation preference and/or researcher reported associations the study was excluded.

During the screening process studies were marked with a tag, consisting out of: Socially disadvantaged groups, non-European context, interventional study, preference study, substitute decision-maker, end-of-life setting, researcher-reported association.

Excluded full text articles were marked by an exclusion reason consisting out of:

-Wrong study population: used in case of not-patient reported data, when there is no subdivision of input of patients and caregivers when included both, in case of pediatric study population or substitute decision-maker
-Wrong outcomes: in case other outcomes then 'barriers and facilitators to participation in SDM' are evaluated (for example decision satisfaction, regret), elements that influence a disease specific choice (for example side effects), engagement in care, participation preference study
-Wrong setting: in case the SDM process is not conducted in a clinical setting between doctor and patient
-Wrong study design: researcher reported associations, interventional study
-Full article not available (in English or for free)

The following hierarchy was used for exclusion reasons*:* Wrong study population > wrong outcomes > wrong study design > wrong setting.

2.4 Study selection- Data collection

Using the review application Covidence© title and abstracts were screened conform the predetermined inclusion and exclusion criteria by 'blinded' reviewers where one (M.L.) screened all studies and two reviewers (S.R. & K.T.) collaborated as second reviewer. A reassessment took place in case of disagreement by two reviewers. Thereafter from the selected articles a full text screening took place in the same manner (M.L., A.B., J.J., VB.P., B.T., K.T.). In case of inclusion or exclusion disagreement between two reviewers in this step a consensus was reached by at least two reviewers.

The application EndNote© (V20) was used to remove duplicates and to manage the bibliography. The results intend to provide an overview of patient-reported barriers and facilitators to participation in SDM, and were organized into categories according to the categorization made up by Joseph-Williams and colleagues [2].

From the final included studies essential key data were selected and bundled in an excel sheet. This data summaries and concerns basic information related to the studies such as author, publication year, study design and objective, country and setting of the conducted study, characteristics of the participants (eg. age and gender). In case any of the desired data is lacking the author of the concerning study was contacted.

2.5 Quality assessment- Data synthesis

Because a big amount of included full text studies the choice was made to apply an in-depth synthesis of selected studies rather than an overall synthesis of the larger number of studies, applying a mixed purposeful sampling strategy.

The data synthesis consisted further out of three steps: intensity sampling, maximum variation sampling and conforming/disconfirming case sampling with the aim to include all studies according to our research goal. Two inclusion criteria were used conceptual overlap and information richness of the articles. So, articles were included where the research question were closest to the one in this study, and the ones including the most data, being defined as being of higher quality. A coding system has been used from 1 to 3, corresponding with low to high relevance. Where one corresponding to the lowest relevance, and three to the highest relevance. Low relevance, code 1 articles were excluded for further analysis. Code 3 articles were used for intensity sampling and code 2 articles were used for confirming/disconfirming case sampling and maximum variation sampling.

In the first step, the intensity sampling, the selected code 3 papers were independently analyzed by two reviewers (M.L., K.T.). This analyze formed the base of the recurring thematic concepts. By maximum variation sampling, conducted by M.L., the concepts were explored more in depth. The goal of maximum variation sampling is to find studies that differ from each other, to increase the variety. This was being achieved by including studies of SDM in different circumstances, different patient population or different setting. In the last step, the confirming/disconfirming case sampling (by M.L.) studies were selected that are outliners, opposing the main selected articles.

3 Results

3.1 Included studies

The initial search reproduced 9265 references without duplicates, wherefrom 209 studies were included conform the inclusion criteria (Figure 1, Flowchart 1). To catch up recent articles during the process a second search was performed. After data synthesis 100 studies remained, whereof 10 articles focusing on advanced care planning (Figure 2, Flowchart 2). The aim subject of this thesis. The study characteristics are presented in Table 1. Table 2 gives an overview of the patient characteristics of the included studies.

Figure 1. Flowchart 1.

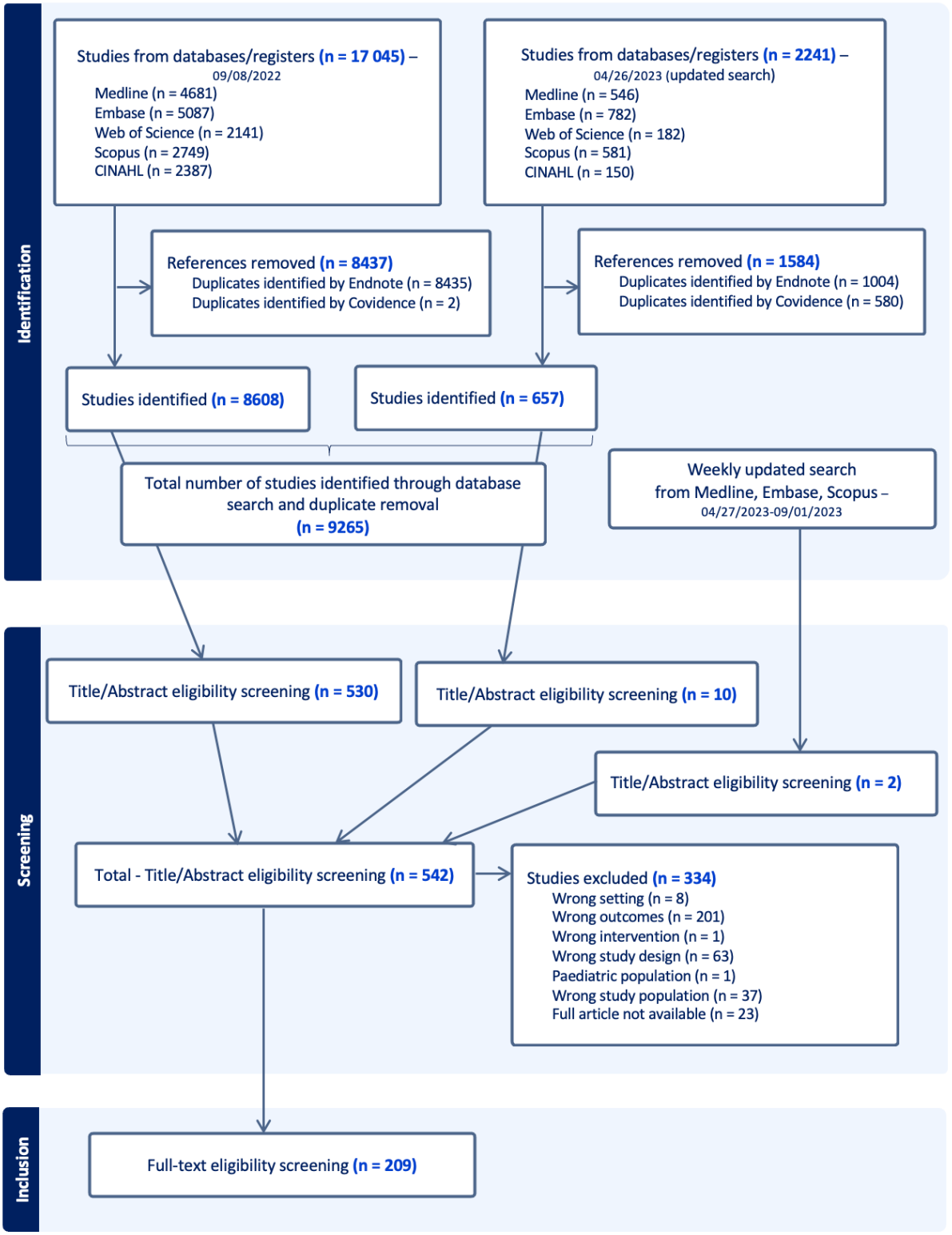
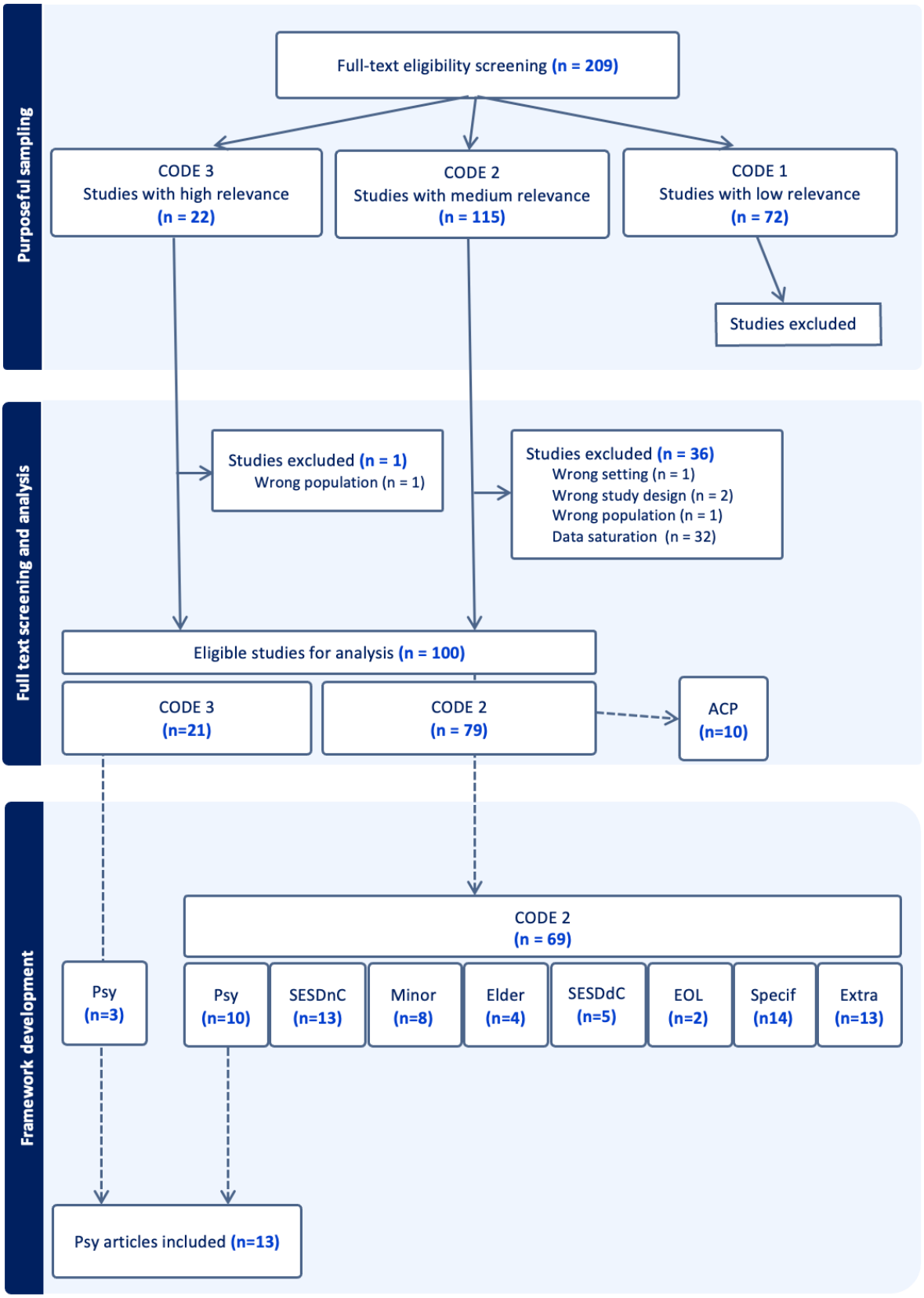


Figure 2. Flowchart 2.



Index:
*ACP = studies about Advanced Care Planning. Analysis in a separate paper will follow.
*Minor = Minority populations in Developed Countries, such as Latinas, African American patients, other patients with differing cultural and ethnic backgrounds from the country they are living in.
*SESDnC = Low SES patient groups in Developing Countries. Countries studied: China (6), Chili (2), Indonesia (1),

Malaysia (1), Malawi (1), Jordan (1), Tanzania (1), Iran (1).
*Psy = Psychiatry or Mental Health setting
*Elder = Elderly patient group
*SESDdC = Low SES patient groups in Developed Countries. Countries studied: United States (1), United Kingdom (1), Germany (1), Netherlands (1), Australia (1).
*EOL = End of Life setting
*Specif = Specific Disease setting, such as: Oncology (10), Obstetrics and Fertility (2), Emergency Department (1), Medically Uncertain situations, diverse (Hypertension, COPD, Diabetes, Heart Disease) (1)
*Extra = studies focusing on one particular aspect of the SDM process, such as: patients' perceived influence of healthcare providers' characteristics on SDM, the influence of patients' subjective norms and social support, the role of preparation and evaluation, the advantages and challenges of family involvement in SDM, the arguments of patients longing for paternalistic role patterns, the importance of physicians' listening behaviour, patients' conceptualisation of involvement,…

Table 1. Study characteristics (n=10)

Author	Year	Country	Aim of the study	Setting	Design
Bernard [44]	2020	Canada	Better understand the barriers faced by older patients regarding talking to their family members and family physicians about ACP.	Family Medicine	Cross-sectional, self-administered questionnaire (including closed ended as well as open ended questions)
Carbonneau [45]	2018	Canada	To investigate patient experiences and perceptions of advance care planning (ACP) process in cirrhosis.	Cirrhosis Care Clinic - Tertiary care setting	Qualitative - Interviews, focus groups
Cheung [46]	2020	China	To explore barriers to ACP from perspective of seriously ill patients and their family caregivers.	Palliative Daycare Center	Qualitative - Focus groups, semistructured interviews (patients, caregivers)
Combes [47]	2021	United Kingdom	To explore the barriers and enablers to advance care planning engagement with frail elders.	Urban hospice	Qualitative - in-depth interviews, thematic analysis
Fenton [48]	2021	United States	To assess knowledge, preferences, and attitudes regarding ACP in individuals with Lynch Syndrome.	Community	Mixed-methods, quantitative (online) survey, follow-up telephone interview
Radhakrishnan [49]	2017	United States	To identify barriers to and facilitators of older South Asian Indian-Americans' (SAIAs') engagement in behaviors associated with	Community	Qualitative - Focus groups (patients, family caregivers, physicians)

			advance care planning (ACP).		
Sellars [50]	2018	Australia	To describe the perspectives and attitudes of patients with end-stage renal disease (ESRD) and their caregivers toward ACP.	Renal services	Qualitative - Semistructured interviews (patients, caregivers), thematic analysis
Shaw [51]	2018	Canada	To explore the readiness among residents, families, and health care practitioners and the factors that influence the degree of readiness.	Community	Qualitative - Semistructured interviews, interpretive descriptive approach
Shen [52]	2020	United States	To understand Latino and non-Latino patients' and caregivers' preferred methods of communicating about ACP.	Outpatient cancer clinics	Qualitative - Interviews
Yonashiro [53]	2016	United States	To explore the knowledge, attitudes, and preferences of older Chinese Americans towards ACP.	Community	Qualitative - Focus groups

Table 2. Patient characteristics (n=10)

Author	**Patient charact-eristics**					**Context**	
	Number	**Health condition**	**Age (mean, range)**	**Male/ female**	**Any remarks**	**Western (US, Australia, Canada)**	**Non-Western (Africa, Asia, South-America, Middle-East)**
Bernard [44]	439	No information	66, 50-95	55,60%	-	1	0
Carbonneau [45]	17	Liver cirrhosis	40-79	17,6% female	Low SES participants	1	0
Cheung [46]	17	Palliative health state	60-80	35,3% female	Chinese setting	0	1
Combes [47]	10	No information	85, 71-95	70% female	80% White British	0	0
Fenton [48]	20	Cancer and non-cancer	48,2, 29-70	85% female	95% White, 95% higher educated	1	0

Radhakrishnan [49]	36	No information	60-95	61% female	South Asian Indian-American sample, 40% lower educated	1	0
Sellars [50]	24	End-stage renal disease	67,55-91	33% female	54% Australian, rest from Africa, Europe and the Middle East	1	0
Shaw [51]	10	No information	72-86	90% female	-	1	0
Shen [52]	20	Advanced cancer	56,51	55% female	Mix of Latino and non-Latino patients, 85% unemployed	1	0
Yonashiro [53]	34	No information	<65 26,5% / 66-74 61.8% / >75 23,5%	64.7% female	-	1	0

3.2 Thematic analysis

From the analysis of the 10 included studies, we withhold four important themes regarding patient reported shared decision making barriers and facilitators in the setting of advanced care planning. These include the medical encounter, the readiness of the patient, the role of social support and the purpose of life. These will be discussed as follows. An overview of all patient reported barriers and facilitators is given in appendix 2.

3.2.1 Medical Encounter

The course of the medical encounter and the doctor's role and skills are important factors of the shared decision making process, especially in advanced care planning (ACP). This consists of various factors that play a role within the gathering with a health care professional, which will be described in the next section.

1 Medical transparency

The content and the amount of the provided information should meet the needs of the patient in the specific time course of the disease [45, 47]. Patients who experience deterioration of their medical condition have the need for more specific information, those who their medical condition is stable prefer information provision and recommendation in a more stepwise manner[47].

In general it is perceived as a barrier when patients get unclear explanations about their diagnosis, prognosis, and treatment options. This especially early in their disease trajectory [45-47]. Mostly the ACP discussion was initiated in case of worsening of the illness [45]. The received information should be frank, direct and clear [45, 47], despite ACP being a difficult topic. Receiving information about the expected progression, the available treatment options, and the possible outcomes is perceived as facilitating [47]. Patients want to know about the harms and benefits and want to be made aware of risks. The feeling that information is being withheld rise feelings of anger and disappointment [50], receiving limited information is reported to hinder discussion [47]. And so on the lack of medical transparency is mentioned as a barrier [50]. Patients report no need for discussing statistics about treatment consequences and options but prefer examples [47]. They rather experience discussing statistics as disturbing [45, 47]. Discussing the provided information in a stepwise manner, by giving targeted information is mentioned as a facilitator [45, 47].

Although, information provision is an important factor in shared decision making, too much information or too many options can be perceived as overwhelming for the patient and may create decisional conflict [46].

Quotes by theme

A Preference of receiving information

- "I want to know everything upfront. I don't want surprises… *I'm okey with that (information) instead of sitting and waiting and wondering what is going to be the outcome. You need to know what could happen.. and how you will function after treatments. It's important to understand what to expect…" [45]*
- *"But they didn't explain what it is"[45]*

B Overwhelmed by options

- *"No. Sometimes there's too much information available. If you don't ask, there'll only be one direction and you go forward. If you know more, you won't know which way is better." [46]*

C Unclear explanations

- *"They are used to talking like that (giving vague explanation). I have seen a lot of doctors doing that." [46]*

2 ACP resources

Additional sources of information are perceived as facilitating, such as video materials or written leaflets [47]. Preferable are videos corresponding to, and specific for each disease [47]. When the information is perceived as complex or too technical it's reported as a barrier [47, 48]. When receiving printed information without any explanation or discussion about the topic it is also mentioned to prevent participation, receiving additional written information next to face-to-face discussion overcomes this barrier [48, 49]. Patients reported it as emotionally difficult when receiving ACP documents without warning or additional support [50]. The use of foreign-language educational materials are being mentioned as facilitators, as reported in the form of a paper brochure in the own language [49]. Another barrier for patient participation is when never receiving any information about advanced care planning during contact moments with health care providers, prior awareness of ACP might overcome this barrier [49].

A need is reported of new tools and support to help patient interaction and discussion about ACP with family members [47].

Quotes by theme

A Need for face-to-face discussion

- *"They always tell me at the hospital...you can pick up some information on your way out and I mean frankly a hospital is probably the last place I [want to] get information because I just want to get in and get out as fast as possible."[48]*

B Too technical resources

- "*I don't know if it's just me being a bit thick, but some of this seems too technical, and if you look at the back it doesn't help." [47]*
- *"I. . . computers are just. . . not within my reasoning at all." [47]*

3 Time and continuity of care

Lack of time during appointments and the tight schedule of the health care professional is reported by patients as a barrier to involve in ACP discussion [44, 46, 49].

Also seeing different doctors during medical encounters makes it difficult to develop a long-term relationship and this may function as a barrier, since these encounters with an unknown healthcare provider could lead to more unclarity [46, 47].

Quotes by theme

A No continuity of care

- "*One doctor would say this, one doctor would say that, nobody could tell me a straight answer… to hell with that" [47]*
- *"Consultations are delivered by different doctors. It is not the same person every time" [46]*

B Time constrains

- *"…Do not allow for an in depth conversation about something that is not happening now or may not ever happen. Appointments are too short" [44]*
- "*Doctor is always too busy. I feel I will impose on his time to talk about this when he has other patients waiting" [44]*

- *"I want to know the diagnosis and prognosis. I want to know what will happen if the condition keeps worsening. But doctors (in acute setting) were really too busy. He (doctor) talked with me in the corridor. That's depressing." [46]*
- "*Family doctors are busy people and I would not consider it appropriate to 'visit' and discuss a broad topic like end of life" [44]*

4 The doctor's role and skills

Since ACP is not always an easy subject to discuss, and sometimes even seen as 'taboo', the skills of the doctor and the relationship with the patient play a role in the medical encounter [47, 50]. A dedicated healthcare professional who doesn't back down to bring up this topic is reported as facilitating in the discussion [50]. Most patients believe that it's up to the healthcare professional to initiate the ACP discussion, and think the initiation of the ACP discussion is part of the doctor's responsibility [44, 50]. The role of the health care professional in advanced care planning is being appreciated, and there exist an expectation that the doctor should initiate the conversation [50, 51].

To role of the health care professional is seen to facilitate the discussion, provide structure to the conversation, mediate between patient and their family members and make the patient feel more comfortable to discuss avoided topics [50].

Complete trust in the doctor or a trusting relationship can function both as a barrier and a facilitator [45, 48, 49]. Patients state that the clinician who knows them best, should initiate the ACP conversation. When another care giver did this it felt uncomfortable to engage in the discussion [45, 48] However the level of comfort played also a role in engagement, where the provider specialty didn't play a significant role, rather the level of trust did [48]. Complete trust in the health care provider (and in family/children) is reported as a barrier to engage in advanced care planning [49]. The belief exist that the health care professional will make the best treatment decisions [46].

Lack of empathy and lack of communication skills of the healthcare professional, especially in case of difficult conversations (eg. prognosis, illness trajectories) was reported as a barrier [46, 47, 50]. Addressing the patient in an unfriendly manner creates a barrier to discussion [46]. When the topic of ACP is conveyed with a sense of humor this facilitates the discussion, especially with elderly [47]. A right approach has been reported as a gentle interaction, speaking clear language, ensuring understanding, and being listened to. Besides being frank and honest as health care professional [47].

Some patients avoid the ACP conversation because of different reasons. Some are afraid getting influenced by the healthcare professional, others fear a negative impact towards the healthcare professional or within the relationship when bringing up the topic themselves [44].

Quotes by theme

A Providers skills/empathy and lack of it

- "*They are very comfortable talking to me and I am very comfortable talking to them. Yes its hard sometimes for doctors to come out and say things, but I hope they won't feel that way" [47]*
- *"A doctor yelled "if you don't receive the treatment you will die" (in an oncology inpatient setting). From the perspective of patients, such words will make us feel down. So I think doctors, I don't know the reasons, but I think as a professional, the best way to communicate is not to say those words to a person in need ... Sometimes their words are discouraging." [46]*
- *"It's how you actually approach it and go about it is a main point, I think. Some people you've got to approach sensitively and others, like me. . . normal conversation, you know." [47]*

B Responsibility

- "*If a doctor wanted to talk to me about the end of life, it would not be hard for me to do" [44]*
- *"He would have to suggest the discussion; MD should bring it up" [44]*
- "Yeah...in that case, I think it should be the doctors that sit down and talk to you." [51]

C Fear of negative impact

- "*Not knowing if his beliefs and values are the same as mine" [44]*
- *"I am not sure that my doctor and I totally agree on treatments" [44]*
- *"I don't want to be unduly influenced by him" [44]*
- *"it's a personal family matter" [44]*
- "*I may be influenced to say my thoughts" [44]*
- "Not the sort of thing you bring up [in] conversation"[50]

D Trust

- *"We're not all going to be the same. To know your patient, you know their personality. You know what they can take. Whereas talking to somebody you don't really know all that well, you don't know what to expect" [45]*
- *"...as far as the primary care doctor, I don't know if I would initiate it with her just because...normally our meetings are...a physical and that's about it." [48]*
- *"...It probably should be your primary care physician but...it depends on who you personally feel you have the best relationship with." [48]*
- *"Personally, I will let the doctor make decisions for me. If he thinks treatment is needed, then I trust him. I always agree with doctors." [46]*
- *"First, it is because I trust him (doctor). Second, He won't do something bad for me because 'Doctoring is parenting' (a Chinese old saying). If he believes he can save that patient, he must do it. If he thinks (he can't) ... then no need to waste resources." [46]*
- *"They don't get to be professional at their jobs without learning by all their patients' experiences. And therefore I'm. . . happy to go along with their professionalism and their experience and their ideas." [47]*

3.2.2 Readiness

Besides the encounter and relationship between doctor and patient, the insight, experiences, mental and physical state of patients, next to their experiences, available resources and their environments plays a role in the decision-making process.

1 Insight of the patient

When patients are unfamiliar with the term 'advanced care planning' or have misunderstandings about it, this impairs involvement [44, 45, 47, 48, 51]. Patients also report a general lack of understanding about the topic [45, 47]. Some think it's about planning the funeral, the financial will,… and think it focuses solely on preparing for death [47, 51, 53]. When asked about engagement in advanced care planning, especially to (frail) elderly, some only recognize or remember involvement only when the advanced care planning process was being described and not by using the terms [47, 51]. Patients also state not knowing enough about ACP, that it is unclear, which makes them engage less in the advanced care planning discussion [48]. Some think involvement is not needed as someone else will take care of it anyways [44].

When patients experience incompetence readiness in understanding details related to treatment options it creates a barrier for involvement, resulting in doctor centered decision making [46]. This is more seen among patient groups who doesn't speak the local language [53]. Patients don't realize they have treatment options and in case of higher mortality they have the choice to withdraw from therapy [50]. When patients have goals, accept their disease and don't want to continue interventions at all costs, involvement becomes much easier [51].

Also, the lack of awareness of the possibility of early discussion when still being in 'good health' plays a role, patients think they cannot participate because they will not be able to do so at the end-of-life stage [46]. They don't understand the process and role of advanced care planning [47]. The worry exists that discussing advanced care planning means an expectation of deterioration [45]. They are afraid that basic health care will be denied in case of traumatic events, which makes patients involve less in end-of-life discussion [49]. The misunderstanding is higher in populations with other cultural background [49]. On the other hand, some view ACP as countering futile medical interventions at the end-of-life which makes them more willing to be involved [50].

Quotes by theme

A Unfamiliarity and misunderstanding of 'ACP'

- *"I would've liked to have known right from the beginning, what levels are going to happen next" [45]*
- *"What are the other options to manage symptoms?" [45]*
- *"I just want the goal to be recovery and not just management of deterioration. I don't want there to be an expectation of deterioration" [45]*
- *"Did not know about [advance] care planning; I think my family will know what to do" [44]*
- *"I would follow any instructions from doctors, because I don't know what (treatments) should be done as the following steps. So just let them decide."* [46]
- *"Put it aside, like an insurance you hope to never use" [45]*

- *"At that moment (end of life) I am already...how can I make a decision? I will leave it to my family for sure." [46]*
- *"Well I've heard the name [advance care planning] but I've no idea, other than guess work, what it is. [Researcher: What would your guess work be?] Oh, about if you die, where you want to be and that kind of thing?" [47]*
- *"Well until this happened to me and I had to start having care, you don't think about it [advance care planning]. . . I never experienced anything like it as such until they started to come for me, all these carers and people. And yeah obviously it's a good idea in lots of ways because lots of people when they get old and helpless, they do need help." [47]*
- *"I thought he was giving me a choice, and he wasn't giving me a choice at all, so I don't really know why he asked the question. He should've explained it a different way, you know what I mean? [If] he [had] said "in your present condition, the advice is that we can't do this [cardiopulmonary resuscitation] because it would do more damage than good." That, I would've understood, but to say "Would you like to be resuscitated?" "Yes please!"'[47]*

2 Health as a factor in timing of ACP – Lack of relevance

The belief that a patient is 'too young' or 'too healthy' (eg. being in good health) impairs the involvement of ACP discussion [47, 53]. More often patients had the opinion that discussions about advanced care planning should take place when health declines, at the onset of severe illness or when death seemed inevitable [49, 53]. However, at the other hand some had the belief that one should think about ACP being in good health, taking into account the uncertainty of life [48]. Patients sometimes worry that negative symptoms of the illness might affect the decision-making ability [45]. It should be considered that time is needed for the patient to accept their diagnosis and prognosis, starting the ACP discussion too early might impair involvement. However, it is reported that some patients initially refused to involve in ACP but after did [46, 50]. Severely ill patients might initial not be ready for advanced care discussion but are after accepting their diagnosis [46, 50]. Concluding ACP should be introduced relatively early to allow the patient the time to reflect and process their prognosis in case of end-of-life decision making. Some patients are aware of the fact that it is better to take initiative and not waiting until being actual ill [45]. Patients who were older or chronically ill seems to be more open and willing to discuss ACP and speak about end-of-life [50]. Not accepting being severely ill function as a barrier of ACP discussion [50].

Sometimes patients are not aware of the possibility early discussion and the importance of it, which results in delay of having the advanced care planning discussion [46].

Some patients, especially frail elders don't always see the relevance of advanced care planning, as such believing there is 'no need to plan' [47], sometimes not being ready to engage, but acknowledging the benefits of ACP for others [47]. They find it futile, because the not stable state of health status [47]. Others just don't see it as a priority [44]. This is also related to their health status as discussed earlier.

Quotes by theme

A Being too young, too healthy

- *"Did not see this this as necessary, it's a bit soon. I am only 80" [44]*
- *"I feel that I am too young for making those types of decisions" [44]*
- *"Not a priority as a healthy person" [44]*
- *"I am not at that point in my life. If I was diagnosed with a terminal disease, then I would talk with him" [44]*
- *"I did not [have a conversation with my doctor] because I am still in good health. So my doctor never say, hi, you have high blood pressure, what do you want to do when you are dead or whatever? So I never talk to her about that." [53]*
- *"I think when nothing happens yet, there is no need to talk to our family about anything. Not until the doctor tells us that we have an incurable disease should we talk to our family about the arrangements or our wishes. Otherwise they will think there is something very wrong with us." [53]*
- *"People in good health do not need to think about preparing a living will."* [48]

B Uncertainty of life

- *"I think that everybody needs a living will. I don't care if you're in good health or not, you never know what tomorrow will bring…it is not guaranteed for anybody." [48]*
- "*You don't know what's going to happen and that's why I think earlier the better because later you might not be all there and that's very important" [45]*

C Lack of relevance

- *"I'm too preoccupied" and "I have thought about it but just haven't acted on it yet". [44]*

- *"Haven't really felt the need for it as yet. And I've only just reached 80. I was feeling unwell a couple of weeks ago, to the point where I was thinking I was on my way out, but it turned out to be a couple of infections that I had that treated with antibiotics cleared up in very short time." [47]*

3 Emotions

The emotional load of the topic of ACP and end-of-life is a barrier to involvement in discussion. Some patients just want to focus on positive aspects, which impairs ACP discussion [44, 46]. The feeling of powerlessness functions as a barrier. Patients have the feeling despite what they do, the outcome is the same, death [46]. The feeling of uncertainty (of the disease trajectory) impacts the readiness to engage in decision making [45]. However, when being aware of the importance of advanced care planning, it helps to overcome negative and uncomfortable feeling and involve in discussing end of life preferences [48].

Quotes by theme

A Emotional load

- *"…Scares me, it is very negative and would depress me" [44]*
- *"Those who smoke can get lung cancer. Those who don't smoke can also get lung cancer. How to explain? I rather trust that is my fate. If you are destined for getting it, you can't avoid it. If not, you won't get it even you smoke or drink a lot ... Just let it go if it cannot be cured" [46]*
- *'it's a little frightening to talk about dying" [44]*
- *"Sad emotional topic" [44]*

4 Prior awareness and experiences

Prior experiences with ACP and decision making, made it easier to engage, providing perspectives and comfort with the topic and so on stimulate the readiness [51]. In general, previous personal health experiences and experiences of surroundings function facilitating [51]. However, in some cases previous experiences function as a barrier, especially in case of frail elders. The obstacle is that they believe someone else would make the decisions for them, their experiences with poor care, or having a health, social care or legal background [47].

Also for patients with another cultural background prior experiences and awareness thought family members or health care professional is reported as a facilitator for engagement in advanced care planning discussion [49].

Quotes by theme

A Prior personal experiences

- "*You know, that's a tough one for me to answer having never had occasion to think about it...I am very independent, I make my own decisions. I take it day by day*" [51]
- *"...After I got through that operation and got back home, I realized that there was things that people should've known if I hadn't have made it through. You know?" [51]*

B Experiences with surroundings

- "*...I've watched my mother and my dad, my sisters, you know, my brother. And to me, those kinds of things have to be planned ahead because strange things happen to people. Like my brother got ALS*" [51]
- *"The life support, yes. If it comes to that, if they have to put me on life support, please don't do that because now my sister's daughter and mother is having the same problem. She was sick too. She was in the hospital for 3 months now. Now, she's gone to kidney failure. But the daughter can't take the responsibility. She can't shake and let go. She's still holding onto her. The doctor has given her there's no hope. So I don't want that." [49]*
- *'Well, care planning, a lot of people want to dot the "I's," cross the "T's" and want to make sure that you're going to go into hospital or you're going to go to [hospice], and you're going to be looked after. And sometimes it happens and sometimes, it doesn't happen. I mean you make all the plans in the world and you can do what my son did, get out the car and drop dead. . . There's no guarantee that it is going to happen, and this is where my carer comes in. I'm afraid she's right. . . what will be will be. What's the song say? Que sera, sera [what will be, will be" '[47]*

5 Setting

Patients prefer to discuss ACP outside of the hospital and receiving initial information about ACP in a nonclinical setting, as it is neutral and non-confrontational setting. This counts for local patients as patients with another cultural background [45, 49]. To stay at home in the end-of-life fase, surrounded by family and everything known is a facilitator to involve in discussion [47].

Barriers for people with an emigration background to involve in ACP discussion exist about concerns about complicated caregiving at home, preference to receive end-of-life care in the hospital due to positive earlier experiences and whether returning to the country of origin to receive and-of-life care (which is preferable in their eyes) or not [49]. On the other hand, the preference to receive care at home or in a hospice worked facilitating [49]. Proximity of loved ones, as well as geographical as emotional is reported as being a facilitator in the engagement of ACP discussion [49].

Quotes by theme

A Setting and culture

- *"I am afraid to be in a hospital and scared for myself. It is much freer to be in my home, but movements are restricted in a hospital. Nobody visits you in a hospital except the doctors." [49]*
- *"In India it's easy for that kind of care. Somebody, taking him to the bathroom, somebody running the house, cooking this, that. For me to have him here it would be really, really difficult." [49]*
- *"One might have town hall meetings, at library, that sort of thing. Where we give out this information. Then, it's easier to approach it with the family member who comes with the elderly person. Then it's easier to, when you're going home, and then the mother also maybe there, may feel comfortable, talking about it because it has become an open issue now." [49]*

B Preference to stay at home

- *"If I had to have medication or injections, I would rather have it at home. I would rather stay at home as long as possible, and pass away peacefully at home with my wife around me or my family around me." [47]*

6 Resources

Patients who lack resources are more willing to involve in ACP discussion. On the other hand, those who already experienced high-quality care and had a good medical insurance didn't feel the urge to plan for end-of life care [49].

Quotes by theme

A Resources

- *"Who is going to take care of us in that old age, because our children are all working? They have their own career. There can be a lot of monies involved in the treatment. Very expensive, very, very expensive. They cannot spend out of their pocket. So that gets our apprehension. That's our fear in the back of our mind. What if we all fall sick? How are they going to cope with it? " [49]*

3.2.3 Social support

The support of family and others plays an important role and function as a barrier and facilitator. Patients in general avoid being a burden to others and take family opinions into account, in some cases even at their own expense, and benefit from non-family support.

1 Avoidance of being a burden

Patients often do not want to bother or burden family or cause them emotional pain, as so communication or expressing thoughts about advanced care is being avoided, this is also seen in the case of frail elders [45-47, 49]. Patients don't want their family members to see them in a critical state [45]. ACP is reported as a strong emotional topic, for the patient as well as the family, acting as a barrier to discussion [44]. To achieve not burdening family some patients reported to want caregivers to make decisions on their behalf, even when the own wishes are not always considered [50]. However some patients reported it's better to initiate the discussion rather than waiting for the children to do so, as taking responsibility in it and making sure the children will know what to do at the end of life [53]. Some believed the discussion about end-of-life care should occur after the diagnosis of severe illness,

to not unnecessary burden or worry the family members [53]. However, in general there exist a need for information and guidance about how to have and initiate these difficult ACP discussions with family members [45].
The topic goes further than just avoiding burdening family, even some had the opinion that society shouldn't be burdened. Having the opinion no money should be spent to keep them alive [50].
Not only the relationship from the patients towards their family members play, but family members might influence the ACP decision and process too, as discussed next.

Quotes by theme

A Avoidance of being a burden to family

- "*We've talked about my disease but I look healthy.. family look at you and think you look okay. You've never thought, sat down and said.. this is what should happen*" [45]
- *"I try to have these discussions with my children and they say you're not dying. They don't want to think about it. It becomes very hard. It is emotional for my wife too, but she understands more*" [45]
- "*Causing emotional pain to family members*" [44]
- *"At this stage, you cannot burden your family. My wife and I are of similar age. It's already very good if she can take care of herself, isn't it? How can she take care of you (me) as well? Our sons and daughters have to work or go to school. This (talking with family) will only bother them.*" [46]
- *"It's better for the parents to bring it up first. Otherwise, the children might worry that [by bringing up this topic with their parents] their parents will feel like the children are trying to curse that they are dying" [53]*
- "*I think a better way is to bring it up casually. Just try to imply [to] them what I want and they'll know. If we hold a family meeting to talk about it, it might sound so serious that it will make our family very upset, and they won't stop thinking about it, but if we just have a casual conversation about it, they will be less nervous and when the time comes, they'll know what to do." [53]*
- *"It's like, something where you know you're gonna be alright, in a certain way. But you know some people [family] might struggle. And you don't want it to spoil their life, thinking about something, you know, that they could have done or not done." [47]*
- *"Up until a certain point, I would be thinking about him [son] . . . and how he's coping with it. [Researcher: So looking after him is important.] Mmm, and the grandchildren because they are young. . . .just as long as I know that there's somebody there to help him as well, afterwards." [47]*
- *"We are dead to the world, but they're suffering because they're looking at us. So we don't want that for them."* [49]
- *"She will be nervous. This (information disclosure) will only pose a burden on her. Her life should end peacefully." [46]*

B Not burdening society

- "*Government shouldn't spend millions to keep [patients] alive once they can't do things" because "if the brain doesn't work there's no use wasting money."* [50]

2 Family dynamics

The family plays an important and significant role in times of illness, especially during periods of worsening of the disease or getting the diagnosis of severe illness [45, 53]. In such cases to promote their autonomy at the end of life, patients felt the need to communicate their preferences with loved ones [53]. However in some cases terminally ill patients tend to leave decisions, due to strong trust, to family members and/or doctors and by that means avoiding decisional conflicts which makes them participate less in the shared decision making process related to ACP [46].
At one hand being in good health, functions as a barrier to discuss ACP with family [45] -so not only with the medical professional-, at the other hand this is also reported as the moment to prevail the own wishes in case family members would disagree upon the preferred choices and decisions [45]. So in case of family involvement the health status might be as well as facilitating, as functioning as a barrier in the ACP discussion, depending on the patient's own coping mechanism.
The relation with the family, eg. the family dynamics and whether having family or not plays also an important role. There exist some concerns, especially in groups of low SES, about lack of (family) support [45]. Also some worry exists about the possibility that family makes bad decisions [45], fear of lack of trust [44] or that discussing ACP might affect the family dynamics, as causing conflict [44, 48]. These insecurities and worries may motivate the patients to take more control about the situation and involve in ACP discussion, by means to avoid such negative situations [44].

As the family role can be supportive, in some cases the family can put pressure on patients to continue treatments which could be avoided by ACP discussion [50]. Especially for frail elders relationships had an impact on decision making, where full trust in family members left the decision making process totally in the hands of family or professionals, which is a clearly barrier [47].
Related to the readiness to engage in the ACP process is the clarity of roles which each involved individual play, in such case patients and family members have a clear idea of their role and a better shared decision making process can be achieved [51].

Quotes by theme
A (Lack of) family support

- *"I'm lucky that my husband was able to help, but there are times when he's found it frustrating." [45]*
- *"I'm still in complete control of everything but he's there when I need" [51]*
- *"My daughter doesn't talk to me. I have no family, no nothing. I don't really have any friends, so what am I supposed to do?" [45]*

B Lack of or full trust in family and role clarity

- "*My wife, she looks after me and she knows a lot about all his stuff.. what she says, they listen, so I don't have to say very much. I'm quiet." [45]*
- *"What if they say leave him in pain forever, he owes us?" [45]*
- *"I don't want any arguments arising*" [44]
- *"Because when the times comes, then the fight starts. Maybe one of your children doesn't want to let go so when you have a personal directive that child stops and you get the make those decisions when you're in a healthier place." [45]*
- *"I don't trust them very much to leave this kind of decision to them" [44]*
- "*My daughter didn't ask my preference ... I don't care what she has discussed with doctors. She knows me very well." [46]*
- *"The family will be there, and they can make...they would be all there to make a decision if they had to be" [51]*
- "*Our children need to know what we think. It's our own business, our decision. Just tell them not to prolong our life or procrastinate our death" [53]*
- *"They've all got their heads screwed on, and they know what's best, and they'd say, you know, he's better off this way, better off that way, and I trust them entirely. . ." [47]*

3 Leveraging support

Not only the support of family plays a role, but also non-family members might also influence the decision making process regarding APC. As patients have the need to be sure that their wishes at the end of life will be accepted, it would be valuable for them to involve (like-minded) surrogates [50]. Counseling services are being proposed to enhance the communication with family and so on the ACP discussion, where it is expected that such counselors also take into account the patient's faith, religion and background [52]. Some patients preferred to speak to a counselor or social worker above a medical professional [48]. Also support groups were reported as facilitating, especially for people with another background (Latino's) to communicate with other patients and to be encouraged to communicate care preferences [52].

Quotes by theme
A Leveraging support

- *"Maybe with them like having someone to talk to them, like a counselor, do you understand?...That would be good, for someone to talk with the family...To explain and tell them that they have to speak clearly with me... My family could speak easier. Talk about it, talk things with more clarity." [52]*

4 Culture and family

It should be noted that patients with other cultural backgrounds (eg Latino's) might have other family dynamics. Generational differences should be taken into account as well as immigration experiences, here there exist a higher wish to involve relatives into discussion [52].
The role of the family should not be underestimated, as there exist a preference of involving the family broadly. Besides that the expectation exist that the doctor should be aware of this and should actively involve the family broadly, which works facilitating [52].

Quotes by theme

A Cultural differences in families

- *"I would [like to talk to family members about care preferences]. I'd be open to it because, see, since I'm the first generation of actually living in the United States and born in the United States, we might have differences." [52]*

B Broad involvement of family

- "*With my relatives. Yes, I mean, it'd be in a group with the doctor and my family... They [providers] don't ask if you want the family to be present and for me, I don't know, I'd always want my family to be present." [52]*
- "*They're the ones who are going to mourn me and know what I want.*" [52]
- *"By talking with them, gathering them together or calling them on the phone, or when I go to chemo, or whatever. In fact, they have always been around and have given their opinions and ideas, too. And I think it's important to get your children involved, even your grandchildren...I think they have been very involved, and that's essential to me. Because their decision is very important, or their opinions, rather than decisions". [52]*

3.2.4 Life view

1 Belief

Religious belief has an influence on the discussion about care with family and providers. There exists a wish for the patient that the provider is aware of that. This regarding also who is involved in the conversation. Religious patients reported to want a member of the church included in the advanced care planning conversation with the doctor, or to be able to acquire advice from religious counselors [52].

Believing in an external loci of control, a higher power [52] or the feeling of fatalism is a barrier for ACP discussion [49].

Quotes by theme

A Belief and ACP

- *"If I'm in the hospital, [the member of the church should be] in the hospital. If I'm at home, [the member of the church should be] at home." [52] (*
- *"God is first. I always tell them [i.e., doctors] that God is first. I will do this because I'm a firm believer, I have faith, and I believe. First, I think I always put my religion first." [52]*
- *"Coming from the Indian perspective and the way the culture, the religion and everything governs you is it will happen. There's always a way. There's a planned way, it's going to take place. I think that's the idea and that's why they don't attach so much importance to it." [49]*
- *"I strongly believe in God and all...while they said my treatment will be for life, for the rest of my days or years, I am sure at some point there will be a more beneficial treatment, and I will be cured." [52]*

2 Autonomy

Feeling able to make a choice relieves patients from depression and indecision regarding their disease [50]. By being willing to engage in ACP discussion, patients report to promoting their autonomy [53].

Quotes by theme

A Maintaining autonomy

- "M*ake a choice," "move on," and "live the rest of their life as positively as possible."* [50]
- "*Our children need to know what we think. It's our own business, our decision. Just tell them not to prolong our life or procrastinate our death*"[53]
- *"I would not want my family making medical decisions at the end of my life" [44]*
- "you don't know what's going to happen and that's why I think earlier the better because later you might not be all there and that's very important" [45]

3 Life and death

When accepting the inevitability of death and trying to stay positive it functions as a barrier to ACP discussion [46]. Pain, suffering and the quality of life influences the engagement in ACP, as quality of life is chosen over longevity and prolonging life sustaining treatments [48, 49]. Life itself is mentioned as a facilitator for ACP discussion [48]. On the other hand some patients are more interested in discussing 'living well now', 'framing a life worth living' and maintaining the quality of life, instead of discussing ACP. Living well was defined as maintaining mobility and independence, and continuing to

have tasks and hobbies to feel valued and useful, being listened to, being surrounded by the right equipment and environment, being supported by family, friends and professionals [47, 50].
Patients, especially frail elders who see death and dying as part of life didn't feel the urge to make future plans [47]. Elderly people might have considered their medical care wishes, and are often interested in limiting health care interventions, taking into account the burden of long term or intensive treatments which didn't seem worthwhile [51].

Quotes by theme

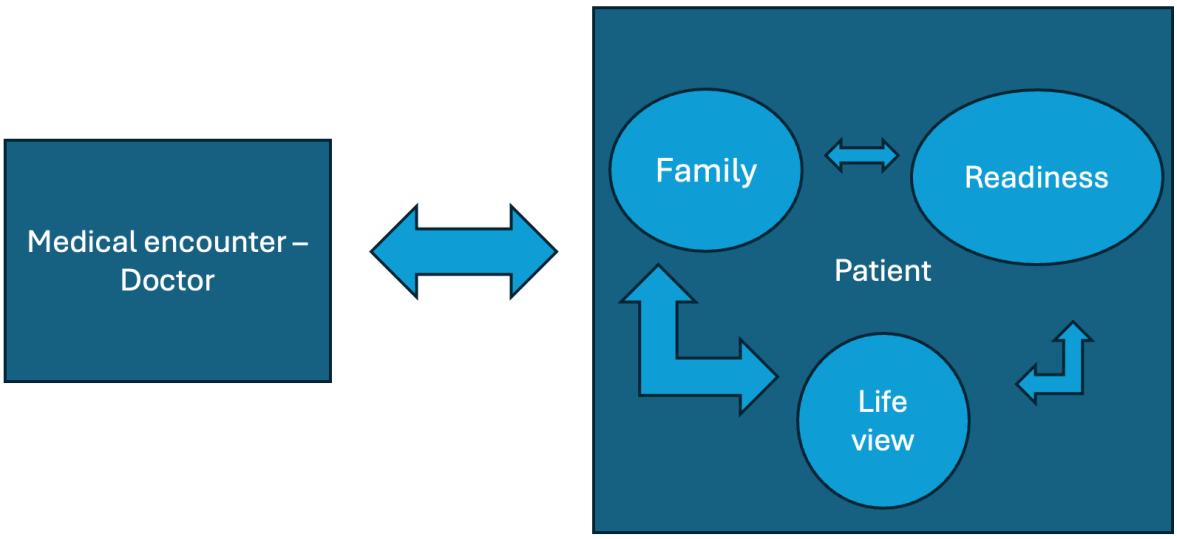
A view of life, accepting death

- *"To be honest, absolutely not (for medical information seeking). At our ages, death is inevitable. The most important aspect of one's life is happiness. I have talked with doctors and have said I don't care (about prognosis and treatments) ... If the doctors say 'no' (illness progression), then I will pretend to be fine." [46]*
- *"Everybody has a confirmed expiry date. It's better to respect that." [49]*

B the future, quality of life

- *"Somebody said to me the other day about thoughts of the future and I thought, well, only, erm, this makes me a bit weepy; not because I'm sad but it's just talking about it. Erm, the future - the only future is erm, getting ill or collapsing and dying [laughter]. I mean er, that sounds charming, doesn't it? But that really is the future." [47]*
- *"I dread the day that might come, when I will not be able to get out of bed. That's why I'm doing these exercises quite, earnestly, but that [being confined to bed] really would be the last straw for me." [47]*
- *"If I can even get up off the chair and walk around with a Zimmer frame, I'd love to make a cup of tea for my wife, that would be it." [47]*
- *"I've got to find whatever I can do, just to feel as though I'm helping out." [47]*
- "You really do have to start thinking about this and thinking, 'Do I really wanna have thirty days of treatment?'", "We discussed it...if I need life support I don't want it and, if my brain's still working then they can just help me by giving me a little help just to get back into shape, that's okay", "Well, you're treating it now so let's not put me through a lot more stuff than I might have to go through." [51]

Figure 3. Interaction of themes.



*Medical encounter: role and skills doctor, medical transparency, time course, ACP recourses
*Family: family dynamics, family interactions, leveraging support
*Life view: culture, religion/belief, autonomy
*Readiness: recourses, setting, prior experiences, emotions, insight in ACP, timing/health status

4 Discussion

4.1 Key findings

From this research four important topics emerged, each consisting of different dimensions and their interconnectedness (see Figure 3). Four themes were identified consisting out of the medical encounter, readiness, social (family) support and the view of life, as discussed earlier.

The last two reported themes are most typical for shared decision making in the advanced care planning setting. The role of the family plays a much larger role, and how a patient approaches life and death becomes an additional topic. Additionally, the readiness of the patients plays a significant role. Readiness is essential for ACP to be conducted [54]. Having ACP discussiosn is only fruitful when the patient feels ready, taking into account emotions and the right timing [54, 55]. In the case of readiness, we observed slight differences in ACP barriers and facilitators compared to those in the case of SDM discussion in other settings. The emphasis is different, but the mentioned topics are recurring.
In the case of shared decision making Keij et al. identified eight elements of patient readiness, where here we can see that mainly all the elements come back [56]. However the element of 'emotional distress' plays the most prominent role in advanced care planning [56]. The confrontation with the end of life is distressing [54].

When looking at the shared decision-making process in terms of several levels, analogous to the description in the scoping review by Zagt et al., we observe in the setting of advanced care planning that mainly the micro level plays an important role [57]. The micro level describes the relationships between patient and healthcare professionals, between patients and the physicians in particularl, and between patients and their relatives [57]. The course of the 'medical encounter' shows the most similarities with SDM patient-reported barriers and facilitators outside the setting of advanced care planning [2]. This encounter is solely an interaction with the patient and the healthcare professional, while in all other identified themes in this study we see involvement, influence and interaction with others. This can be traced back to the micro level [57], (Figure 3).

The role of the family becomes more significant and has been mentioned as controversial. Also in literature it's reported as a complex topic regarding to ACP [58]. Family involvement shifts dynamics, as on one hand there might exist full trust in the health care professional, but in case of advanced care planning, the topic of full trust in family members rises – next to that in the healthcare provider, or even above it.

Recent literature points out to culture-related factors and their influence on ACP involvement [59, 60]. In other cultures the Western autonomy concepts are more relational than the individual [59].
It is remarkable that the topic of life and death in the Western study population is more subtle [61], which we see also in our results, and the focus lies on autonomy and quality of life. In some cultures, death is seen as a taboo topic [62]. This reflects a way of life, however it was less emphasized in the conducted interviews. However, we should consider the selective number of included studies.

In the case of religious patients and/or patients with a non-Western background, their beliefs and family dynamics play a much more prominent role, resulting in a shift in reported barriers and facilitators among ethnic and racial minorities [63]. The spiritual needs and concerns during advanced care planning conversations might differ [64]. It has been reported that nonwhite patients are more likely to involve in ACP or to be aware of the concept compared to white patients [65]. In case of Hispanics and Asian patients a significant preference is reported for family-centered decision making [65]. Studies investigating shared decision making, advanced care planning and spirituality are limited [66]. Culture and the existence of generational differences has an influence on how patients deal with and view ACP [62]. Cultural influences on ACP have been investigated [60]. It has been reported that

sociodemographic elements, experiences, health status, literacy and cultural values/spirituality have an impact on ACP engagement among ethnic minorities [63]. However, an overview of barriers and facilitators from the patient perspective seems rare in the literature, especially for a broad range of ethnic minorities, for whom studies focusing on Asians, Japanese Americans or Latinos have been reported [63].

Previous research has demonstrated ACP barriers which are conform our study findings, including having insufficient knowledge [59, 67, 68], the unpredictability of the disease and prognosis [59, 67], the hesitation to discuss ACP with the health care professional (emotions) [59, 67, 69, 70] and the existing expectation that the health care professional should initiate ACP discussion [59, 69]. These findings corresponds mainly with the subthemes of the 'medical encounter'.
The topic of not wanting to bother family members and having full trust in them also comes back in the literature [71].

4.2 Implications for practice and future research

Overcoming the barriers of involvement in shared decision making for the Western population is already challenging for health care professionals. We suggest that it should be the task of the health care professional to remove the existing misconceptions about ACP, during the medical encounter taking into account the appropriate timing to do so. It has been reported that knowledge and understanding can also overcome the barrier of emotions [48].
However, doing so in the case of a growing multicultural society is even more challenging, given the different underlying layers and interactions, of which healthcare professionals might not always be aware. This itself becomes a barrier in the interaction. A possible language barrier can interfere with the medical encounter, which influences the readiness of the patients. The bigger role the family might play, the desire to involve others broadly (family and leveraging support) and the possible family-dominant decision-making might collide with the usual ongoing ideas of the health care provider and further interactions between patient and health care professional. Additionally, the belief of the patient in a higher power or an external locus of control is reported as a barrier [52], which might prevent further discussion and interaction altogether, and could even influence the course of the medical encounter.

It could be questioned whether another approach is required. For example, accepting the wish of patients having ACP discussions in a nonmedical setting where experiences are shared and not just medical facts, and involving leveraging support. Normalizing the involvement of medical support staff, who can have more time for patients to discuss their values and wishes in a nonformal setting might support the process. It can become a standardized process during the intake of new patients, as a way of getting acquainted to report what are the values of the patient, how the family dynamics is, are there religious or spiritual aspects involved… It might already plant a seed for the health care professional to navigate to the ACP discussion when needed. Given the fact that patients who have already notion of ACP makes them involve more often [51].

Further research should focus on tools to educate healthcare professionals to initiate and guide the advanced care planning process on one hand, and tools to support patients in this journey on the other hand, with side steps considering patients with different cultural backgrounds or belief/spirituality. This applies to all levels of the four mentioned themes. Further research on the role of patients' existential beliefs in the ACP discussion across different sociocultural patient groups could contribute to the insights into patients' perspectives on ACP. Barriers and facilitators should be explored more between the major religions and cultures instead of focusing on selective groups or countries [66, 72]. Concerning the involvement of family in the advanced care planning process, initial attempts are being made to create guides for family integrated ACP [71].

4.3 Strengths and limitations

This review is unique by giving a detailed overview of patient reported barriers and facilitators of shared decision making in the setting of advanced care planning. This was a subtheme within a bigger research question. As mentioned earlier the decision had been made to opt for a detailed analyze of selected articles rather than a more superficial data collection of a broader range of articles.

The included articles in this review are an excerpts of a larger pool of articles, with here n=10. Because this limited amount the studies could be analyzed in detail. A larger number of included studies in this review might provide more material for comparison and provide even more nuances. However, we see similarities with other studies, which acts as a quality control, in addition to new findings. Also, in the selection process we aimed to include studies with the most variety and disconfirming cases, doing so reducing the risk of confirmation bias.

The focus of the study was on patient reported barriers and facilitators, and not on patient characteristics which are also known to influence the SDM process. This choice was made because mainly patients characteristics are not changeable and are intertwined with other elements. However, in reality these characteristics are indispensable in the SDM process.

It should be taken into account that most data in the included studies was obtained by questioning patients, which can be considered as a 'a snapshot', which might influence the results.

As we also observe cultural roles and differences, the results may also be depended on which country the study was conducted which might result in slightly different results after analyses of a broader cultural population.

We chose to focus on non-interventional studies, with the consequence that we cannot make any expression about it. It should be considered that we clustered the findings in themes, which are not exclusive and sometimes overlapping.

4.4 Conclusion

We can conclude that there are similarities and important differences between patient-reported barriers in shared decision making and those in advanced care planning discussion. We withheld four important themes regarding patient reported SDM barriers and facilitators in the setting of advanced care planning. These include the medical encounter, the readiness of the patient, the role of social (family) support and the purpose of life. The last two reported themes are most typical for shared decision making in the advanced care planning setting. The role of the family plays a much larger role, and how a patient approaches life and death becomes an additional topic. Additionally, the readiness of the patients plays a significant role. Readiness is essential for ACP to be conducted.

Further research is needed to map out tools to overcome the abovementioned barriers, emphasize the reported facilitators, and acknowledge the role of family and spirituality in the process.

5 Bibliography

1. Hoffmann, T.C., et al., *Shared decision making: what do clinicians need to know and why should they bother?* Med J Aust, 2014. **201**(1): p. 35-9.
2. Joseph-Williams, N., G. Elwyn, and A. Edwards, *Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making.* Patient Educ Couns, 2014. **94**(3): p. 291-309.
3. Elwyn, G., et al., *A three-talk model for shared decision making: multistage consultation process.* Bmj, 2017. **359**: p. j4891.
4. Elwyn, G., D. Frosch, and S. Rollnick, *Dual equipoise shared decision making: definitions for decision and behaviour support interventions.* Implement Sci, 2009. **4**: p. 75.
5. Elwyn, G., D.L. Frosch, and S. Kobrin, *Implementing shared decision-making: consider all the consequences.* Implement Sci, 2016. **11**: p. 114.
6. Hargraves, I. and V.M. Montori, *Decision aids, empowerment, and shared decision making.* Bmj, 2014. **349**: p. g5811.
7. Hargraves, I.G., et al., *Purposeful SDM: A problem-based approach to caring for patients with shared decision making.* Patient Educ Couns, 2019. **102**(10): p. 1786-1792.
8. Couët, N., et al., *Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument.* Health Expect, 2015. **18**(4): p. 542-61.
9. Légaré, F. and P. Thompson-Leduc, *Twelve myths about shared decision making.* Patient Educ Couns, 2014. **96**(3): p. 281-6.
10. Stiggelbout, A.M., A.H. Pieterse, and J.C. De Haes, *Shared decision making: Concepts, evidence, and practice.* Patient Educ Couns, 2015. **98**(10): p. 1172-9.
11. Berger, Z., et al., *The submissive silence of others: Examining definitions of shared decision making.* Patient Educ Couns, 2022. **105**(7): p. 1980-1987.
12. Ubel, P.A., K.A. Scherr, and A. Fagerlin, *Empowerment Failure: How Shortcomings in Physician Communication Unwittingly Undermine Patient Autonomy.* Am J Bioeth, 2017. **17**(11): p. 31-39.
13. Driever, E.M., A.M. Stiggelbout, and P.L.P. Brand, *Shared decision making: Physicians' preferred role, usual role and their perception of its key components.* Patient Educ Couns, 2020. **103**(1): p. 77-82.
14. Caverly, T.J. and R.A. Hayward, *Dealing with the Lack of Time for Detailed Shared Decision-making in Primary Care: Everyday Shared Decision-making.* J Gen Intern Med, 2020. **35**(10): p. 3045-3049.
15. Stacey, D., et al., *Are Patient Decision Aids Used in Clinical Practice after Rigorous Evaluation? A Survey of Trial Authors.* Med Decis Making, 2019. **39**(7): p. 805-815.
16. Légaré, F. and H.O. Witteman, *Shared decision making: examining key elements and barriers to adoption into routine clinical practice.* Health Aff (Millwood), 2013. **32**(2): p. 276-84.
17. Joseph-Williams, N., A. Edwards, and G. Elwyn, *Power imbalance prevents shared decision making.* Bmj, 2014. **348**: p. g3178.
18. Barry, M.J. and S. Edgman-Levitan, *Shared decision making--pinnacle of patient-centered care.* N Engl J Med, 2012. **366**(9): p. 780-1.

19. Pollard, S., N. Bansback, and S. Bryan, *Physician attitudes toward shared decision making: A systematic review.* Patient Educ Couns, 2015. **98**(9): p. 1046-57.
20. Briss, P., et al., *Promoting informed decisions about cancer screening in communities and healthcare systems.* Am J Prev Med, 2004. **26**(1): p. 67-80.
21. Levinson, W., et al., *Not all patients want to participate in decision making. A national study of public preferences.* J Gen Intern Med, 2005. **20**(6): p. 531-5.
22. Joseph-Williams, N., et al., *Implementing shared decision making in the NHS: lessons from the MAGIC programme.* Bmj, 2017. **357**: p. j1744.
23. Müller-Engelmann, M., et al., *Shared decision making in medicine: the influence of situational treatment factors.* Patient Educ Couns, 2011. **82**(2): p. 240-6.
24. King, V.J., et al., *Perceptions of shared decision making and decision aids among rural primary care clinicians.* Med Decis Making, 2012. **32**(4): p. 636-44.
25. Say, R., M. Murtagh, and R. Thomson, *Patients' preference for involvement in medical decision making: a narrative review.* Patient Educ Couns, 2006. **60**(2): p. 102-14.
26. Perez Jolles, M., J. Richmond, and K.C. Thomas, *Minority patient preferences, barriers, and facilitators for shared decision-making with health care providers in the USA: A systematic review.* Patient Educ Couns, 2019. **102**(7): p. 1251-1262.
27. Pel-Littel, R.E., et al., *Barriers and facilitators for shared decision making in older patients with multiple chronic conditions: a systematic review.* BMC Geriatr, 2021. **21**(1): p. 112.
28. Willems, S., et al., *Socio-economic status of the patient and doctor-patient communication: does it make a difference?* Patient Educ Couns, 2005. **56**(2): p. 139-46.
29. Muscat, D.M., et al., *Health Literacy and Shared Decision-making: Exploring the Relationship to Enable Meaningful Patient Engagement in Healthcare.* J Gen Intern Med, 2021. **36**(2): p. 521-524.
30. Alsulamy, N., et al., *What Influences the Implementation of Shared Decision Making: An Umbrella Review.* Patient Educ Couns, 2020.
31. Tidhar, M. and J. Benbassat, *Teaching Shared Decision Making to Undergraduate Medical Students.* Rambam Maimonides Med J, 2021. **12**(4).
32. Chewning, B., et al., *Patient preferences for shared decisions: a systematic review.* Patient Educ Couns, 2012. **86**(1): p. 9-18.
33. Kiesler, D.J. and S.M. Auerbach, *Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions.* Patient Educ Couns, 2006. **61**(3): p. 319-41.
34. P. Kramer, E.D., D. Verhue, *Samen beslissen. Doelgroeponderzoek onder zorgverleners en zorggebruikers*. 2020, Kantar: Nederland. p. 77.
35. Gravel, K., F. Légaré, and I.D. Graham, *Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions.* Implement Sci, 2006. **1**: p. 16.
36. Morrison, R.S., D.E. Meier, and R.M. Arnold, *What's Wrong With Advance Care Planning?* Jama, 2021. **326**(16): p. 1575-1576.
37. Houben, C.H.M., et al., *Efficacy of advance care planning: a systematic review and meta-analysis.* J Am Med Dir Assoc, 2014. **15**(7): p. 477-489.
38. Rietjens, J.A.C., et al., *Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care.* Lancet Oncol, 2017. **18**(9): p. e543-e551.

39. Brinkman-Stoppelenburg, A., J.A. Rietjens, and A. van der Heide, *The effects of advance care planning on end-of-life care: a systematic review.* Palliat Med, 2014. **28**(8): p. 1000-25.
40. Rosca, A., et al., *Shared decision making and advance care planning: a systematic literature review and novel decision-making model.* BMC Med Ethics, 2023. **24**(1): p. 64.
41. Jimenez, G., et al., *Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons.* J Pain Symptom Manage, 2018. **56**(3): p. 436-459.e25.
42. Munn, Z., et al., *Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach.* BMC Med Res Methodol, 2018. **18**(1): p. 143.
43. Page, M.J., et al., *The PRISMA 2020 statement: an updated guideline for reporting systematic reviews.* Bmj, 2021. **372**: p. n71.
44. Bernard, C., et al., *Exploring patient-reported barriers to advance care planning in family practice.* BMC Fam Pract, 2020. **21**(1): p. 94.
45. Carbonneau, M., et al., *Patient Views on Advance Care Planning in Cirrhosis: A Qualitative Analysis.* Can J Gastroenterol Hepatol, 2018. **2018**: p. 4040518.
46. Cheung, J.T.K., et al., *Barriers to advance care planning: a qualitative study of seriously ill Chinese patients and their families.* BMC Palliat Care, 2020. **19**(1): p. 80.
47. Combes, S., et al., *The importance of living well now and relationships: A qualitative study of the barriers and enablers to engaging frail elders with advance care planning.* Palliat Med, 2021. **35**(6): p. 1137-1147.
48. Fenton, V., et al., *Assessing Advance Care Planning in Individuals with Lynch Syndrome.* SN Compr Clin Med, 2021. **3**(2): p. 562-569.
49. Radhakrishnan, K., et al., *Barriers to and Facilitators of South Asian Indian-Americans' Engagement in Advanced Care Planning Behaviors.* J Nurs Scholarsh, 2017. **49**(3): p. 294-302.
50. Sellars, M., et al., *An Interview Study of Patient and Caregiver Perspectives on Advance Care Planning in ESRD.* Am J Kidney Dis, 2018. **71**(2): p. 216-224.
51. Shaw, M., et al., *Characterizing Readiness for Advance Care Planning From the Perspective of Residents, Families, and Clinicians: An Interpretive Descriptive Study in Supportive Living.* Gerontologist, 2018. **58**(4): p. 739-748.
52. Shen, M.J., et al., *An examination of Latino advanced cancer patients' and their informal caregivers' preferences for communication about advance care planning: A qualitative study.* Palliat Support Care, 2020. **18**(3): p. 277-284.
53. Yonashiro-Cho, J., S. Cote, and S. Enguidanos, *Knowledge About and Perceptions of Advance Care Planning and Communication of Chinese-American Older Adults.* J Am Geriatr Soc, 2016. **64**(9): p. 1884-9.
54. Zwakman, M., et al., *Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness.* Palliat Med, 2018. **32**(8): p. 1305-1321.
55. Abdul-Razzak, A., et al., *'Conditional candour' and 'knowing me': an interpretive description study on patient preferences for physician behaviours during end-of-life communication.* BMJ Open, 2014. **4**(10): p. e005653.

56. Keij, S.M., A.M. Stiggelbout, and A.H. Pieterse, *Patient readiness for shared decision making about treatment: Conceptualisation and development of the Ready(SDM).* Health Expect, 2024. **27**(2): p. e13995.
57. Zagt, A.C., et al., *A scoping review into the explanations for differences in the degrees of shared decision making experienced by patients.* Patient Educ Couns, 2024. **118**: p. 108030.
58. Boerner, K., D. Carr, and S. Moorman, *Family relationships and advance care planning: do supportive and critical relations encourage or hinder planning?* J Gerontol B Psychol Sci Soc Sci, 2013. **68**(2): p. 246-56.
59. Rietjens, J., I. Korfage, and M. Taubert, *Advance care planning: the future.* BMJ Support Palliat Care, 2021. **11**(1): p. 89-91.
60. McDermott, E. and L.E. Selman, *Cultural Factors Influencing Advance Care Planning in Progressive, Incurable Disease: A Systematic Review With Narrative Synthesis.* J Pain Symptom Manage, 2018. **56**(4): p. 613-636.
61. Lutz, K., S.R. Rowniak, and P. Sandhu, *A Contemporary Paradigm: Integrating Spirituality in Advance Care Planning.* J Relig Health, 2018. **57**(2): p. 662-671.
62. Ha, J.H., C. Lee, and J. Yoo, *Cultural Differences in Advance Care Planning and Implications for Practice.* Omega (Westport), 2023. **87**(3): p. 838-855.
63. Hong, M., et al., *Facilitators and Barriers for Advance Care Planning Among Ethnic and Racial Minorities in the U.S.: A Systematic Review of the Current Literature.* J Immigr Minor Health, 2018. **20**(5): p. 1277-1287.
64. Kwak, J., et al., *Patients' spiritual concerns and needs and how to address them during advance care planning conversations: Healthcare chaplains' perspectives.* Palliat Support Care, 2024. **22**(1): p. 49-56.
65. Kwak, J. and W.E. Haley, *Current research findings on end-of-life decision making among racially or ethnically diverse groups.* Gerontologist, 2005. **45**(5): p. 634-41.
66. Miyashita, J., et al., *Association between religious beliefs and discussions regarding advance care planning: A nationwide survey.* Palliat Med, 2021. **35**(10): p. 1856-1864.
67. Jabbarian, L.J., et al., *Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices.* Thorax, 2018. **73**(3): p. 222-230.
68. Izumi, S.S., et al., *Advance care planning as perceived by marginalized populations: Willing to engage and facing obstacles.* PLoS One, 2024. **19**(4): p. e0301426.
69. Bernacki, R.E. and S.D. Block, *Communication about serious illness care goals: a review and synthesis of best practices.* JAMA Intern Med, 2014. **174**(12): p. 1994-2003.
70. De Vleminck, A., et al., *Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review.* Scand J Prim Health Care, 2013. **31**(4): p. 215-26.
71. Kishino, M., et al., *Family involvement in advance care planning for people living with advanced cancer: A systematic mixed-methods review.* Palliat Med, 2022. **36**(3): p. 462-477.
72. Bülow, H.H., et al., *The world's major religions' points of view on end-of-life decisions in the intensive care unit.* Intensive Care Med, 2008. **34**(3): p. 423-30.

6 Appendix

6.1 Search strategy

Concept 1: Decision-Making	“Decision Making”[Mesh:NoExp] OR “Decision Making"[tiab] OR "Decision Making, Shared"[Mesh] OR “SDM”[tiab] OR “sharing decision*”[tiab] OR “shared decision*”[tiab] OR “decision process*”[tiab] OR “choice making”[tiab] OR “patient choice*”[tiab] OR “patient decision*”[tiab] OR “preference sensitive”[tiab]
Concept 2: Patient Participation	"Patient Participation"[Mesh] OR "Patient Participation"[tiab] OR “Patient Engagement”[tiab] OR “Patient involvement”[tiab] OR "Patient Preference"[Mesh] OR "Patient Preference*"[tiab] OR "Physician-Patient Relations"[Mesh] OR "Physician-Patient Relation*"[tiab] OR “Patient-Physician Relation*”[tiab] OR “Doctor-patient relation*”[tiab] OR “Patient-doctor relation*”[tiab] OR “Practitioner-Patient Relation*”[tiab] OR “Patient-Practitioner Relation*”[tiab] OR "Refusal to Participate"[Mesh] OR "Refusal to Participate"[tiab]
Concept 3: Patient Perceptions	“patient report*”[tiab] OR “patient identified”[tiab] OR “patient related”[tiab] OR “patient-specific”[tiab] OR Perception*[tiab] OR Perspective*[tiab] OR View*[tiab] OR Experience*[tiab] OR “Opinion”[tiab] OR "Attitude"[Mesh:NoExp] OR “Attitude*”[tiab] OR "Attitude to Health"[Mesh] OR "Health Knowledge, Attitudes, Practice"[Mesh:NoExp] OR “Patient Satisfaction”[Mesh] OR "Patient Satisfaction"[tiab] OR belief*[tiab] OR believ*[tiab] OR "Motivation"[Mesh:NoExp] OR "Motivation*"[tiab] OR “Expectation*”[tiab] OR barrier*[tiab] OR obstacle*[tiab] OR block*[tiab] OR difficult*[tiab] OR problem*[tiab] OR hinder*[tiab] OR facilitat*[tiab] OR enabl*[tiab] OR promot*[tiab] OR help*[tiab] OR encourag*[tiab]
Concept 4: Study Design	"Surveys and Questionnaires"[Mesh] OR survey*[tiab] OR questionnaire*[tiab] OR "Interviews as Topic"[Mesh] OR interview*[tiab] OR "Focus Groups"[Mesh] OR “focus group*”[tiab]

6.2 Overview patient reported barriers and facilitators of ACP

Theme	Barrier	Facilitator
1 Medical encounter 1.1Medical transparency	-Unclear explanations -Receiving limited information -Lack of medical transparency -Discussing statistics -Providing too much information or too many options	-Information provision regarding disease status -Providing information in stepwise manner -Frank, direct and clear information -Receiving information about progression, treatment options, outcomes -Providing targeted information -Being made aware of risks, harms and benefits

1.2 ACP resources	-Too technical, complex information -Receiving printed information without discussion -Never receiving ACP information beforehand	-Information sources (video, leaflets) -Information next to face-to-face discussion -Foreign language educational materials
1.3 Time and continuity of care	-Lack of time during appointments -Plural involved health care providers	
1.4 Doctor's role and skills	-(Complete) trust in the health care provider -Lack of empathy, lack of communication skills -Unfriendly approach -Fear of getting influenced -Fear of negative impact towards healthcare professional	-Dedicated health care provider - Good relationship with health care provider -Health care provider initiate ACP discussion -Trust in the health care provider -Using humor -Being listened to, gentle interaction, clear language, ensuring understanding, being frank and honest as healthcare professional
2 Readiness		
2.1 Insight of the patient	-Unfamiliar with term ACP -Misunderstanding about ACP -Not being familiar with ACP -Incompetence readiness -Language barrier -Not knowing having a choice -Not aware of early discussion possibility	-Having goals -Accepting disease status -Countering futile medical interventions
2.2 Health as a factor in timing of ACP – Lack of relevance	-Being in good health -Not accepting being severely ill -Not aware of early discussion -'No need to plan' -Not stable health status -Not seeing ACP as a priority	-Uncertainty of life and being in good health -Time to accept diagnosis -Being older or chronically ill
2.3 Emotions	-Emotional load -Feeling of powerlessness -Feeling of uncertainty	-Being aware of the importance of ACP
2.4 Prior awareness and experiences	-Prior experiences	-Prior experiences, personal and of surroundings, also in case of other cultural background
2.5 Setting	-Emigration background: concerns about caregiving at home, preference to receive end of life care in the hospital, returning to country of origin	-Outside the hospital, non-confrontational setting, also in case of other cultural background - The wish to stay at home at the end of life -proximity of loved ones, geographical and emotional
2.6 Resources	-Experience of high quality care, having a good medical insurance	-Lack of resources

3 Social support		
3.1 Avoidance of being a burden	-Strong emotional topic	-Taking responsibility to support family -Not burdening society
3.2 Family dynamics	-Trust in family members/doctors -Being in good health -Pressure of family	-Worsening of disease, getting diagnosis of severe illness -Being in good health -Concerns about decisions family -Fear, lack of trust of family -Avoiding negative situations -Clarity of roles
3.3 Leveraging support		-Involving like-minded surrogates -Counseling services) -Support groups
3.4 Culture and family		-Involving family broadly
4 Life view		
4.1 Belief	-Feeling of fatalism -Believing in an external loci of control/higher power	-Taking into account religious belief
4.2 Autonomy		-Feeling able to make a choice -Promoting autonomy
4.3 Life and death	-Accepting inevitability of death -Staying positive -Wish to discuss 'life, and living well now' -Seeing death as part of life	-Quality of life -Life itself -Limiting health care interventions