Title: A Literature Review of Possible Barriers and Knowledge Gaps of General Practitioners in Implementing Advance Care Planning in Ireland: Experience from Other Countries

Author names: Karendeep Somal, Tony Foley.
Degrees: Graduate Entry Medicine, University College Cork
Affiliations: University College Cork
About the author: Karendeep Somal is currently a third-year medical student at the University College Cork, Ireland

Acknowledgment: None
Financing: Not applicable
Conflict of interest statement by authors: No conflict of interest
Compliance with ethical standards: Any aspect of the work covered in this manuscript has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

Manuscript word count: 2525.
Abstract word count: 240
Number of Figures and Tables: 7 (3 Figures, 4 Tables)

Professional and Institutional Social Network accounts.
- **Institution Facebook:** University College cork
- **Institution Twitter:** UCC Ireland
- **Authors email:** karensomal@hotmail.com

Discussion Points:
What are general practitioner's understanding of advance care plans?
What are general practitioner's perspectives on advance care plans?
What barriers do general practitioners face in implementing advance care plans into daily clinical practice?

ABSTRACT.

Background: An Advance Care Plan (ACP) is a process of decision-making concerning end of life care that embodies a patient's values and wishes, for a time when patients are unable to make such decisions for themselves. ACPs have been employed into medical practices worldwide; however, they remain largely uncompleted by general practitioners (GPs), regardless of their benefits to patients and their families with respect to end of life (EOL) care. Furthermore, ACPs will soon be implemented into clinician practices across Ireland, as part of the Assisted Decision Making (Capacity) Act 2015. This review aims to explore the literature to examine challenges GPs may face in employing ACPs into clinical practice.

Methods: An electronic search was performed through three databases: PubMed, MEDLINE, and CINAHL Plus, through which a total of eleven studies met the selection criteria. Additionally, three studies were provided by experts in the field. Thus, a total of fourteen studies were condensed and critically appraised through CASP (Critical Appraisal Skills Program), which concluded that the quality of the studies was high.

Conclusion: Through this review, knowledge gaps and barriers for GPs regarding ACPs were identified. Barriers for implementing ACPs into practice were categorized into three major themes: barriers for the GPs, barriers in the healthcare system, and barriers regarding the patient. These included insufficient time, complexity of the ACP documents themselves, uncertainty of the disease prognosis, and the ultimate fear of inducing anxiety and loss of hope in patients.

Key Words: General Practitioners; General Practice; Advance Care Planning; Advance Care; End of Life Care; Terminal Care (Source: MeSH-NLM).

INTRODUCTION

As technological and medical advances continue to improve, the average life-expectancy has correspondingly increased. As the population ages, complications regarding end of life (EOL) care become of great importance. Individuals hold certain preferences concerning their final days, which has created a large demand for Advance Care Planning.

An Advance Care Plan (ACP) provides instructions concerning healthcare practices that an individual may prefer at times when they no longer have the capacity to do so[1,2]. It can be created voluntarily by patients over the age of 18 with decision-making capacity, and only comes into play if they lose this decision-making capacity in the future[2]. ACPs take into consideration patients' beliefs, values, and wishes about their healthcare and treatment preferences with regards to how they die[3,4]. ACPs were originally created in the late 1990s in the United States of America[5]. Although they have been around for many years, their utilization by physicians remains moderately low, especially in regions outside of the USA. It has been described that ACPs are more prevalent in the USA than throughout Europe[6].

There are numerous benefits of ACPs, as they allow patients to gain control of their own health, decrease anxiety regarding death, and ultimately reduce suffering and needless interventions that may unnecessarily prolong life[7,8]. Furthermore, they have been shown to reduce worry and burden on patients' families[4,9,10].

ACPs may progress to advance healthcare directives (AHCDs); however, AHCDs are legally assembled documents, whereas ACPs do not always necessitate documentation, and can be completed merely through discussions between the physician and patient[11,12]. Additionally, AHCDs consider specific limited situations and treatments, and the refusal of such treatments, unlike ACPs[11,13].

It is suggested that ACPs should be conducted by the patient's general practitioner (GP) as they are principally involved in EOL care[14,15]. GPs have developed strong, trusting patient-physician relationships over the years that should facilitate such discussions, as patients may feel more at ease to discuss such material with a trustworthy doctor[14,17]. ACPs are created with patients, their GP, and, at times, family members and other healthcare professionals[14,16]. In order to initiate the process, GPs are required to assess their patient's mental capacity. The capacity to make decisions has been described as, the ability to comprehend the significance and nature of the decision being made in the context of the options available[17]. Moreover, an individual is required to understand, retain, and deliberate the information provided and then be able to effectively communicate their choice[2,17].

The exact completion of ACPs by GPs in Ireland is currently unknown, however it does remain fairly low[18]. Furthermore, there is currently no legislation in action in Ireland to govern ACPs or AHCDs. The Assisted Decision Making (Capacity) Act 2015 was signed into Irish law on December 30th, 2015 to support an individual's decision-making regarding EOL care[19]. However, its commencement remains incomplete, as numerous challenges to the health sector regarding its implementation remain unsettled.

As previously mentioned, it has been advised that ACPs should be completed by a patient and their GP. However, previous studies have illustrated that majority of GPs do not complete ACPs, even though they are shown to improve patient satisfaction and quality of life[16]. ACPs have been shown to increase relationship satisfaction between patients and their families, increase psychological well-being, and ultimately enlist a sense of control in patients[20,21]. Nonetheless, it has been noted that Irish individuals are less likely to plan ahead for their own death, and thus this may create an additional barrier[18]. This review thus aims to identify potential limitations in implementing ACPs into clinics, along with the current understanding and knowledge of GPs regarding ACPs, and the potential barriers they perceive regarding its employment into daily practice.

The aims of this study were to condense and appraise the existing literature regarding GPs persecptives regarding ACPs and their use in everday clinical practice. The specific objectives were: (i) to establish the level of knowledge of GPs regarding ACPs; (ii) to establish the perspective of GPs regarding ACPs; and (iii) to establish the current barriers in implementing ACPs into daily clinical practice.

METHODS

Search Strategy

On 12th April 2019, electronic searches were conducted using a total of three databases to retrieve the relevant articles that may answer the research objectives of this review. The primary search was conducted through PubMed, and EBSCOhost research databases, which include MEDLINE and CINAHL Plus.

The following strategy was assumed: “Advance Care” [Title] AND “General Practice” [All Fields] or “General Pract*” [All Fields]

The equation initially generated 156 results from PubMed, 122 results from MEDLINE, and 45 results from CINAHL Plus. Any duplicates were removed. Inclusion and exclusion criteria, found in *Table 1*, were applied to the abstracts and then to the full articles remaining. This search yielded a total of eleven articles that were used in the review. *Figure 1* details the search selection process. Critical appraisal was carried out on all 14 studies via CASP (Critical Appraisal Skills Program), which concluded that the quality of the studies was high. 13 of the 14 studies used a qualitative methodology, so the CASP qualitative checklist was applied (Supplementary Table 2). Additionally, 2 studies conducted systematic reviews and thus the systematic review CASP checklist was utilized in these cases (Supplementary Table 3).

Selection Criteria

Table 1 depicts the article inclusion and exclusion criteria. Articles that were translated to the English language were excluded from this literature review to avoid errors attributed to translation. Due to the limited amount of research regarding the implementation of ACPs into clinical practice, there was no specific timeframe set for the articles. Also, articles that were not available as free full texts were excluded.

The 323 articles produced from the initial search using PubMed and the EBSCOhost Research Databases were filtered using the aforementioned criteria, and duplicates were removed. This resulted in 48 articles, that were then manually filtered by titles and abstracts. Articles without a methodology section, and articles considering EOL processes other than ACPs were removed, yielding 13 articles. These 13 articles were then reviewed as full-texts. Many articles considered the patient’s perspective regarding ACPs instead of that of the physician, and thus were removed. Furthermore, some articles only considered ACPs for dementia patients specifically and not the wider population, removing such articles yielded 11 articles. In addition, 3 articles were obtained through expert input in the field. These last 3 articles were utilized to create the questionnaire that will be implemented in the future study. Overall, there were a total of 14 articles used in the review to answer the objectives.

A summary flowchart depicting the study selection process is illustrated in *Figure 1*.

RESULTS

The 14 studies included in the review were conducted in the UK, Belgium, Australia, Canada, the USA, and the Netherlands (*Figure 2*). Of these 14 qualitative studies, 5 used semi-structured interviews, 5 used questionnaires, 2 used focus groups, 1 used a systematic literature review, and 1 used both a literature review and focus group approach. All results relevant to the current review are summarized in Supplementary *Table 4*.

Of the 323 relevant articles found, 11 records met the selection criteria. Additionally, 3 studies were included through recommendation by experts in the field; thus, 14 studies in total were reviewed. The use of qualitative methodology was appropriate, as the studies set out to determine the subjective experience and perspective of GPs regarding ACPs. In studies involving interviews, the presence of interview bias was at times unknown. However, one study did mention that interview biases may have played a role, as the interviewer was a member of the faculty that was being interviewed, which may have altered the findings. Furthermore, one of the studies conducting surveys did not base their questionnaire off of a previously validated survey and did not discuss how they developed their own survey. It was therefore assumed that the questionnaire utilized was not validated. Additionally, in one of the studies conducting systemic reviews, the methodology of the included articles was inconsistent, hence combining their results may not be accurate.

Themes

Current Knowledge of GPs regarding ACPs

This review found that the current understanding of GPs concerning ACPs is inadequate. GPs are unsure of when and how to initiate EOL care discussions[2,3,17]. They have not received adequate training regarding ACP documents, including how to initiate such a sensitive topic and whom to include in the process[14,19,22]. It was also shown that ACPs are conducted in a distinct manner, depending on if they are completed in an out-patient versus in-patient setting, and in rural or urban areas[16,23]. No single technique has been implemented in conducting ACPs across different settings, hence, the understanding of ACPs by GPs is fairly poor.

Barriers in Implementing ACPs into Clinical Practice

All fourteen studies revealed overlapping barriers for implementing ACPs into practice that fell into three categories: barriers for the GP, barriers in the healthcare system itself, and barriers involving the patients (*Figure 3*). Each of these will be described independently below.

Barriers for the GP

Twelve studies determined barriers for healthcare workers in conducting ACPs. Nine studies looked solely at GPs[1,3,13,14,16,17,19,22,24]. From these studies, one of the main barriers for GPs included the fear of eliciting anxiety and loss of hope in their patients[2,9,14,16,17,19], as well as imposing personal distress on themselves[1,22]. GPs were also unsure on when to introduce such discussions and whom to involve, such as family members or other healthcare professionals[2,3,14]. Even when ACPs were initiated, many GPs felt a lack of confidence in their abilities, due to their poor understanding of ACPs and scarce EOL care experience[2,3,11,13,16,17,19,22,23].

Barriers in the Health Care System

The current healthcare system has not appropriately prepared GPs to initiate ACPs. Essentially, there is insufficient time available in consultations to complete such a process and provide empathy for family members and the patient themselves[3,11,17,22,24]. Likewise, there is no means of compensation provided for conducting ACPs, which leaves little incentive for GPs to complete them[23]. Additionally, there is no means of communication between GPs and specialist physicians that take over patient care towards the EOL or in debilitating conditions, thus hindering GPs from proceeding with ACPs[1,3,16].

Furthermore, the process itself is tedious and paper-based. As many GP practices have shifted towards electronic databases, paper-based documentation is unsuitable[19,24]. The healthcare system has not created a single system to incorporate ACPs into practice with ease, which impedes physicians' confidence levels regarding their execution[16,17].

Barriers Involving the Patient

ACP discussions can involve family members; however, many members may be in denial of their loved one's diagnosis or have disagreements concerning their preference of care. This can result in added difficulty for physicians to commence the necessary modifications required to ensure that patients' EOL care needs are met[1,13]. Multiple studies concluded that lack of understanding of the diagnosis, disease trajectory, and available treatment options for both the GP and the patient were probable barriers[2,3,11,17,23,24]. Additionally, patients lack an understanding of ACPs, as no information about ACPs is provided to patients, which in itself, hinders such a process[24]. It was also illustrated that many patients' requests are vague and may change overtime, making it difficult to meet their needs based on the resources currently available in the health system[2,3].

DISCUSSION

This review attempted to explore the current knowledge of GPs regarding ACPs, and the barriers that exist concerning their implementation into everyday clinical practice.

Knowledge of GPs regarding ACPs

GPs were unsure of when to initiate such discussion with regards to diagnoses, as patients and their families require time to understand and come to terms with their illnesses[2]. Differences amongst GPs also occurred when defining ACPs, as GPs in rural and urban regions had divergent opinions and understanding of the process itself[16].

Barriers for ACP Implementation

Studies found that previous experiences with ACPs and EOL care improved the skills of GPs and thus facilitated discussions[3]. However, De Vleminck et al (2013) found that younger GPs were more likely to initiate discussions compared to older and more experienced physicians. Therefore, future studies are needed to determine the influence of years of experience on ACP employment.

There were contradictory findings regarding the length of relationship between the physician and patient and the ease of ACP discussions. Having a stronger relationship with the physician allows patients to feel comfortable when discussing such topics[2,14,17,24]; however, it was suggested that having such a relationship with patients may actually hinder GPs' tendencies to participate in such discussions, due to the emotional impact it causes them[1]. Nonetheless, GPs had no concern that having such discussions with their patients would ruin their relationship[24]. Thus, obtaining further information regarding patient-physician relationship dynamics and the ease of implementing ACPs is needed.

Results regarding interprofessional teams and ACPs also varied. Some studies found that involving other health professionals facilitated EOL discussions, as they specified treatments available that GPs may be unaware of[2,24]. While others discovered that other health professionals lacked role understanding, which resulted in inadequate communication between team members, and ultimately hindered the overall process[3,16].

Direct comparison of these studies is difficult, as each one used different methodologies. The studies that utilized questionnaires had developed their questionnaires in a distinct manner and had included diverse questions. The sample sizes of 8 of the 14 studies was fairly small, and, thus, the findings may not be applicable on a larger scale. As participation in all studies was voluntary, it is uncertain if the findings are truly representative of the greater population. Similarly, the process of data collection could introduce biases, as many of the surveys and interview questions were not validated or provided in the articles themselves. Also, the studies included in the analysis were not conducted in a similar manner, thus results obtained could differ amongst the studies themselves. Additionally, only full free texts were included in this review, which does not represent all of the data available. Furthermore, as only one individual evaluated each of the papers in this review, the chance of error in interpretation is not fully removed.

The studies involved did not restrict their use of ACPs to a certain group of illnesses and can be applicable to ACP implementation for a wider array of diseases and health conditions. Likewise, GPs from diverse regions

were incorporated into the studies, suggesting that the findings can be applied on a larger scale. Additionally, many of the studies had one lead researcher transcribing and encoding the data, which eliminates biases regarding data analysis.

Conclusion

It has been suggested that ACPs should be completed by patients' GPs, as they play a central role in the care of patients, yet numerous barriers regarding its completion in clinical practice have been revealed. Lack of knowledge and time, and the fear of provoking anxiety in patients were all found to be potential barriers. There is a lack of data assessing the understanding and knowledge of Irish GPs regarding ACPs, as the Irish healthcare system greatly differs from the studies explored in this review. There is however, an increased need to effectively understand the potential barriers and knowledge of Irish GPs, as ACPs will be incorporated into clinical practices in Ireland through the Assisted Decision Making (Capacity) Act 2015 in the near future.

REFERENCES.

1. Brazil K, Carter G, Galway K, Watson M, T van der Steen J. General practitioners perceptions on advance care planning for patients living with dementia. BMC Palliat Care. 2015 Apr 23;14(14).
2. Fletcher S, Sinclair C, Rhee J, Goh D, Auret K. Rural health professionals' experiences in implementing advance care planning: a focus group study. Aust J of Prim Health. 2016 Nov;22:423-427.
3. Fan E, Rhee J. A self-reported survey on the confidence levels and motivation of New South Wales practice nurses on conducting advance-care planning (ACP) initiatives in the general-practice setting. Aust J of Prim Health. 2017 Apr;23:80-86.
4. Dingfield L, Kayser J. Integrating Advance Care Planning Into Practice. Chest. 2017 Mar 6;151(6):1387-1393.
5. Sabatino C. The Evolution of Health Care Advance Planning Law and Policy. Milbank Q. 2010 Jun;88(2):211-239.
6. Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V et al. Advance Care Planning in Belgium and The Netherlands: A Nationwide Retrospective Study Via Sentinel Networks of General Practitioners. J Pain and Symptom Manage. 2011 Oct;42(4):565-577.
7. Detering K, Hancock A, Reade M, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010 March 24;340:c1345.
8. Ries NM, Douglas M, Simon J, Fassbender K. Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs. Médecins, avocats et planification préalable de soins: innover et travailler ensemble pour satisfaire les besoins du client. *Health Policy*. 2016 Nov;12(2):12-18. French.
9. Mullick A, Martin J, Sallnow L. An Introduction to Advance Care Planning in Practice. BMJ. 2013 Oct 21;347:f6064.
10. Busa C, Zeller J, Csikós Á. [Who should decide at the end of life? International practice of advance care planning and possibilities for adaptation in Hungary]. Orv Hetil. 2018 Jan;159(4):131-140.
11. De Vleminck A, Houttekier D, Deliens L, Vander Stichele R, Pardon K. Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: a phase 0-1 study. BMC Palliat Care. 2016 Feb;15(17).
12. Lam L, Ansari AS, Baquir PJ, Chowdhury N, Tran K, Bailey J. Current practices, barriers and enablers for advance care planning among healthcare workers of aged care facilities in western New South Wales, Australia. Rural and Remote Health. 2018 Nov;18:4714.
13. De Vleminck A, Pardon K, Beernaert K, Deschepper R, Houttekier D, Van Audenhove C et al. Barriers to Advance Care Planning in Cancer, Heart Failure and Dementia Patients: A Focus Group Study on General Practitioners' Views and Experiences. PLOS ONE. 2014 Jan 21;9(1):e84905.
14. Boyd K, Mason B, Kendall M, Barclay S, Chinn D, Thomas K et al. Advance care planning for cancer patients in primary care: a feasibility study. Br J Gen Pract. 2010 Dec;60(581):e449-e458.
15. Cartwright, CM, Parker, MH. Advance care planning and end of life decision making. Aust Fam Physician. 2004 Oct;33(10):815-819.

16. De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R et al. Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. Scand J Prim Health Care. 2013 Dec;31(4):215-226.
17. Hajizadeh N, Uhler L, Pérez Figueroa R. Understanding patients' and doctors' attitudes about shared decision making for advance care planning. Health Expect. 2015 Dec;18(6):2054-2065.
18. Weafer J, Murphy S, Foley S. IHF Perspectives 4 A Perspective on Advance Planning for end-of-life. Dublin; 2016 March.
19. Detering K, Hancock A, Reade M, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010 Mar 23;340:c1345-c1345.
20. Minto F, Strickland K. Anticipating emotion: a qualitative study of advance care planning in the community setting. Int J Palliat Nurs. 2011 Jun;17(6):278-284.
21. Singer P, Martin D, Kelner M. Quality End-of-Life Care. JAMA. 1999 Jan 23;281(2):163.
22. Rhee J, Zwar N, Kemp L. Why Are Advance Care Planning Decisions Not Implemented? Insights from Interviews with Australian General Practitioners. J Palliat Med. 2013 Oct;16(10):1197-1204.
23. Howard M, Bernard C, Klein D, Tan A, Slaven M, Barwich D et al. Barriers and Enablers to Advance Care Planning with Patients in Primary Care: A Survey of Health Care Providers. Can Fam Physician. 2018 Apr;64:e190-e198.
24. Scholten G, Bourguignon S, Delanote A, Vermeulen B, Van Boxem G, Schoenmakers B. Advance directive: does the GP know and address what the patient wants? Advance directive in primary care. BMC Med Ethics. 2018 Jun 11;19(58).

FIGURES AND TABLES.

Figure 1. Selection Process Flow Chart

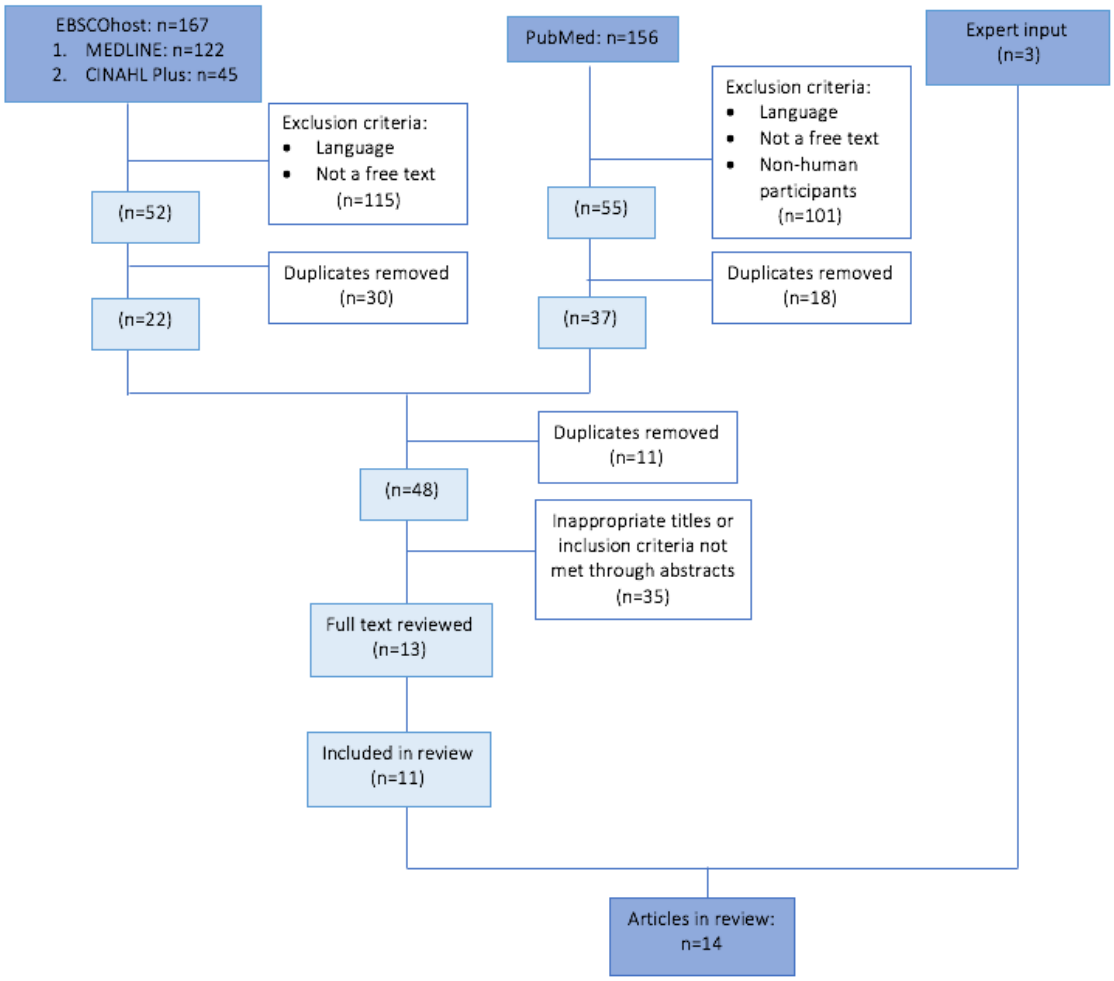


Figure 2. Demographics of Included Studies

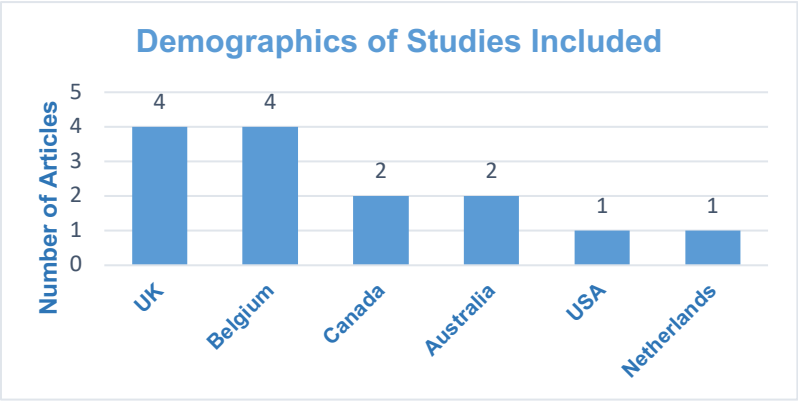
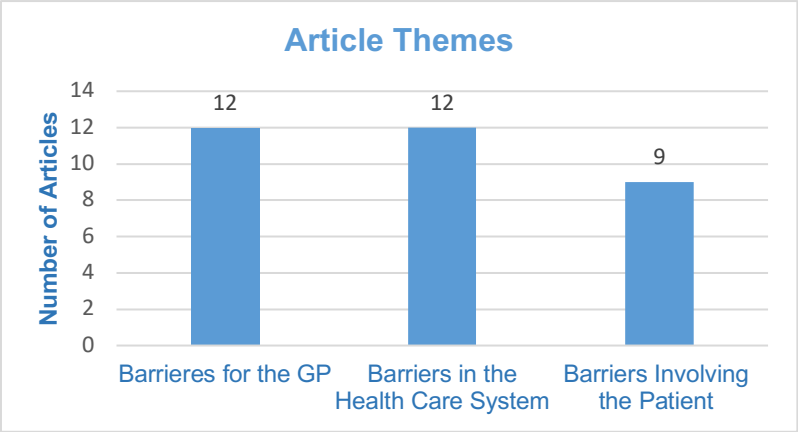


Figure 3. Major Themes of Articles



1 **Table 1**. Selection Criteria

Inclusion Criteria	Exclusion Criteria
Assessed GPs perspectives towards ACPs	Articles not available as free full texts
Evaluated GPs' knowledge of ACPs	Studies not written in English
Evaluated barriers for GPs regarding ACPs	Studies conducted on animal populations
Assessed ACPs implementation into clinical practice	Studies were part of book chapters
Studies conducted on the human population	
Studies available in English	
Articles available as free full texts	

2

3

Supplementary Material

Supplementary Table 2: Summary of Critical Appraisal Skills Program (CASP) Qualitative Checklist Findings

Reference	Boyd et al. (2010)	Minto F., and Strickland K (2011)	Rhee J.J., Zwar N. A., and Kemp L. A. (2013)	De Vleminck et al. (2014)	Hajizadeh N., Uhler L.M., and Perez Figueroa R.E. (2014)	You et al. (2015)	Brazil et al. (2015)	Fletcher et al. (2016)	De Vleminck et al. (2016)	Fan E., and Rhee J.J. (2017)	Howard et al. (2018)	Scholten et al. (2018)	Wichmann et al. (2018)
Clear statement of aims?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Methods appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Research design appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Recruitment strategy appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Data collection appropriate?	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Relationship bias minimized?	Unknown	No	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ethical?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sufficient data analysis?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Valuable findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Supplementary Table 3: Summary of Critical Appraisal Skills Program (CASP) Systematic Review Checklist Findings

Reference	Clearly focused question?	Right papers?	All relevant studies included?	Quality of included studies?	Result combination reasonable?	Overall results?	Precision of results?	Application of results?	Important outcomes considered?	Benefits vs. harms?
De Vleminck et al. (2013	Yes	Yes	Yes	U	No	Yes	Yes	Yes	Yes	Yes
De Vleminck et al. (2016)	Yes	Yes	Yes	U	Yes	Yes	Yes	Yes	Yes	Yes

1 **Supplementary Table 4**. Summary of Studies

Author, (Year), Location, Title	Objective(s)	Study Design, Sample Size	Key Findings (relevant to current study)	Strengths	Limitations
Boyd et al. (2010) **Scotland, UK** **Advance care planning for cancer patients in primary care: a feasibility study**[14]	To assess the feasibility of implementing ACP in general practice	Mixed methods (including semi-structured Interviews and telephone interviews) 20 GPs and 8 community nurses N=32	• Younger doctors had no experience of ACPs compared to older doctors • GPs keen to undergo training regarding EOL discussions • GPs considered experience with ACPs more beneficial than knowledge about ACPs Barriers for ACP discussions: • Fear of destroying coping strategies and eliciting fear in patients • Unclear understanding of ACPs • Paper-based documents	• Considered a diverse group of primary care professionals not just solely GPs • Same researcher conducted all interviews	• Workshops discussed slightly different topics • All participants initially had no understanding of ACPs • GPs with experience with oncology only enrolled • Different interview environments as Interviews were conducted at each GPs practice, or over the phone, • Only considered 4 GP practices
Minto F., and Strickland K. (2011) **Scotland, UK** **Anticipating emotion: a qualitative study of advance care planning in the community setting**[19]	To explore experiences of GPs and direct nurses involved in EOL care and ACP To find factors that hinder or assist ability to engage in ACP and EOL discussions	Semi-structured interviews 3 GPs and 3 direct nurses N=6	• Mixed results on the impact of GP-patient relationship dynamics and ease of ACP discussions Barriers for ACP discussions • Emotional impact on GP • Inability to meet patient's expectations regarding treatment and EOL care based on the resources available • Availability of equipment was a bigger issue than time constraints and workload • Sense of guilt if unable to deliver care that patient desired • Difficult to support family members	• The same lead researcher transcribed and conducted each interview • Interview recordings were verified and edited by participants to ensure no loss of meaning	• Unknown if having a nurse conduct ACPs would allow for better care due to their relationship dynamics with the patient • Different interview environments as Interviews were conducted at each GPs practice • Small sample size (n=6) • Lead researcher was a clinical nurse specialist which could have led to biases in the results
De Vleminck et al. (2013) **Flanders, Belgium** **Barriers and facilitators for general practitioners to engage in advance**	To determine the factors that hinder or facilitate GPs in engaging in ACPs	Systematic review 16 articles	Barriers for ACP discussions: • Unaware of when to initiate discussion + whom to approach • GP's ack of knowledge and skills • Vague requests made by patients • Belief that GPs role is to cure • Fear of upsetting patient • GP's uncertainty of disease trajectories	• Articles included came from diverse countries • Considered barriers from the perspective of the physician and the healthcare system itself	• All studies used different methods thus unable to combine for meta-analysis • Biases in articles chosen and their findings

care planning: a systematic review[16]			• No initiation by the patient • Patients' knowledge of illness diagnosis/prognosis/trajectory Facilitators for ACP discussions: • GPs having a living will themselves • Attitude that a GP should initiate EOL discussions • Longstanding relationship with patient • Consultation with other HCWs • Younger GPs more likely to initiate discussion • Legal support • Financial compensation for time spent on ACPs	• Systematic steps conducted twice by two different reviewers	
Rhee J.J., Zwar N. A., and Kemp L. A. (2013) **Australia** **Why Are Advance Care Planning Decisions Not Implemented? Insights from Interviews with Australian General Practitioners**[22]	To determine factors that influence ACP implementation from the GPs perspective	Semi-structured interviews N=17	• Mixed feelings on legal status of ACPs and ease of implementation Barriers for ACP discussions: • Accessibility/ease of ACP documents, especially in after-hours and emergencies • Patients' knowledge of illness diagnosis/prognosis • Patient's being in denial • Patient's family dynamics • Not being able to meet patients' wishes due to over-investigations	• Interviews conducted by the same person • Asked exact same questions • Transcribed by a professional agency • Participants recruited through various manners, thus representative	• Use of open-ended questions makes it difficult to analyze the data • Small sample size • Interview was conducted by a GP (response bias)
De Vleminck et al. (2014) **Flanders, Belgium** **Barriers to advance care planning in cancer, heart failure, and dementia patients: a focus group study on general practitioners'**	To identify barriers for GPs in initiating ACPs To determine the different barriers for GPs between health conditions	Focus groups N =36	• Many were not familiar with the term ACP • Many GPs had conducted ACPs previously but in an informal manner with no documentation • Previous positive experiences facilitated ACP discussions Barriers for ACP discussions: • Lack of communication between specialists and GPs • Decreased contact between GPs and cancer patients due to transfer of care • GP's knowledge and confidence levels	• Considered various illnesses (cancer, heart failure, and dementia) and barriers for initiating ACPs individually • Had rural and urban focus groups to determine if any differences were present	• Focus groups did not consist of equal number of participants • Mainly male and older GPs in study • GPs with experience in palliative care • Changed topic of focus group after the first two groups were completed • Small sample size

views and experiences[13]			• Lack of time • Uncertainty of when to initiate discussions • GP's personal beliefs • Uncertainty of disease trajectories • No initiation by the patient • Patients' knowledge of illness diagnosis/prognosis/trajectory • Change in preferences by patients over time	• Translated by two researchers • Considered barriers from the perspective of the physician and the healthcare system itself	
Hajizadeh N., Uhler L.M., and Perez Figueroa R.E.. (2014) **New York City, USA** **Understanding patients' and doctors' attitudes about shared decision making for advance care planning**[17]	To determine the current use and attitudes regarding shared decision making and ACPs	Semi-structured Interviews 11 Patients and 5 doctors N =11	• Most doctors prefer SDM, yet they ultimately seem to be making the final decision for the patient • Doctors strongly believe that they should be involved and initiate EOL discussions • Doctors believe that ACPs should be conducted in the community and not hospitals, mainly with their GPs Barriers for shared decision making: • Different cultural backgrounds • Language barriers • Lack of patient empowerment • Patients' knowledge of illness diagnosis/prognosis • Lack of time • GP's understanding of illness prognosis	• Interviews were closed-ended questions and easy to quantify • Interviewers were all trained in a similar manner • Transcribed via a constant comparative analysis	• Only 5 doctors were interviewed (small sample size) • Interviews were conducted by different people • Participants were largely white middle-aged males • Difficult to interpret interviews
You et al. (2015) **Canada (British Columbia, Alberta, Ontario, Manitoba, and Newfoundland and Labrador)** **Barriers to Goals of Care Discussions with Seriously Ill Hospitalized Patients and Their Families**	To determine hospital-based physicians' perspectives about: • Barriers impeding communication and decision-making regarding goals of care with terminally ill patients and their families	Cross-sectional Self-administered web and paper questionnaires N=1256	Barriers for ACP discussions: • Patient and family's difficulty in prognosis acceptance • Patients and family's' knowledge of illness diagnosis/ prognosis/trajectory • Lack of agreement amongst families regarding EOL care • Lack of patient's capacity Minor barriers for ACP discussions • Legal concerns • Lack of knowledge and skills • Lack of time	• Survey developed in 3 stages • Both web and paper surveys • Very large sample size • Variety of HCWs enrolled (nurses, residents, and physicians) • 13 hospitals enrolled • 77.7% response rate	• Only considers hospital-based clinicians not GPs • Did not consider all hospital HCWs that could possibly take part in ACPs • Response bias • Recall bias • HCWs were all from teaching hospitals

	• Their willingness and acceptability to engage in this process			• Physicians in 5 different provinces enrolled • Questionnaires were specific to each HCWs role • French and English surveys used and translated by bilingual members for accuracy	
Brazil et al. (2015) **Northern Ireland, UK** **General practitioners' perceptions on advance care planning for patients living with dementia**[1]	To determine preferences and attitudes of GPs regarding decision-making for patients with dementia	Cross-sectional posted survey N=133	• GPs require training on discussing ACPs with families • GP's relationship with the patient and their family facilitates discussions Barriers for ACP discussions: • Uncertainty of when to initiate conversation • Uncertainty of disease prognosis • Early discussions triggered anxiety in patients • Lack of family's understanding of therapies and prognosis	• 61% of the surveyed practices provided a response • Mean years of practice was 24.7 years	• Mixed reviews on when EOL discussions should be held • Did not consider how to provide information and understanding to families • Only considered GP practices with registered dementia patients • Responder bias
Fletcher et al. (2016) **Western Australia** **Rural health professionals' experience in implementing advance care planning: a focus group study**[2]	To identify the: • Perceptions of HCWs with ACP • Systemic issues regarding ACP • Training needs for ACP	10 focus groups consisting of GPs, GP registrars, and nurses N=55	• Different HCWs have a different understanding of ACPs • ACPs are conducted differently in hospital and community-based practices • Rural and urban GPs have differences in opinion on whether or not to document ACP discussions Barriers for ACP discussions: • Lack of knowledge and confidence • Lack of time • Unable to preserve hope in patients • Complexity of ACPs • No single system on how to develop ACPs • Interprofessional teams and lack of role understanding	• Used intra-professional focus groups instead of interprofessional to eliminate power relationships from playing a role • Data analyzed by the same researcher	• Only considered rural HCWs • Qualitative study – interpretation methods • Small sample size

			Facilitators for ACP discussions: • Previous positive experience with ACPs		
De Vleminck et al. (2016) **Brussels, Belgium** **Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: a phase 0-1 study**[11]	To develop an intervention to support ACP in general practice To identify the barriers and facilitators for GPs to engage in ACPs To identify the attitudes and concerns of GPs regarding initiating ACPs	literature review and focus groups n = 36	Barriers for ACP discussions: • Lack knowledge/confidence • Lack of time • Unsure of components of ACPs • Uncertainty of when to initiate conversation • Worry of creating anxiety or decreasing hope in patients • Uncertainty of disease trajectories • Patients' knowledge of illness diagnosis/prognosis • No central system to document patient's wishes • Inability to determine capacity • Legal implications • Uncertainty about the usefulness of ACPs Facilitators for ACP discussions: • Positive experiences in past • Patient brings up topic • Long-term relationship with patient	• Considered diverse barriers and implemented interventions to overcome • Considered barriers from the perspective of the physician and the healthcare system itself	• Small sample size • Unknown if interventions implemented would be used widely or how feasible they are to implement into everyday practice
Fan E., and Rhee J.J. (2017) **New South Wales, UK** **A self-reported survey on the confidence levels and motivation of New South Wales practice nurses on conducting advance-care planning (ACP) initiatives in the general-practice setting**[3]	To understand practice nurses' beliefs, attitudes, and confidence regarding ACPs To identify the potential barriers and challenges regarding ACPs	Online cross-sectional survey N=147	• ACPs should not be solely done by GPs • ACPs should be conducted in the community and not hospitals Barriers for ACP discussions: • Uncertainty of patient's capacity • Lack of funding and time • Uncertainty if wishes will be met • Uncertainty of disease prognosis and trajectory • Personal discomfort • Patients knowledge of ACPs • Lack of information regarding ACPs for patients Facilitators for ACP discussions:	• Survey was created by a team with expertise in ACP and palliative care, that consisted of GPs and registered nurses • 82% completion rate of survey	• Most nurses were female • Mainly consisted of rural nurses • Actual knowledge about ACPs was not tested • Responder bias

			• The Patient-nurse relationship dynamics influence ease of discussion • Perceived knowledge of ACPs correlated with discussion confidence • Training enhances confidence		
Howard et al. (2018) **Canada (Ontario, Alberta, and British Columbia)** **Barriers to and Enablers of advance care planning with patients in primary care: survey of health care providers**[23]	To identify barriers to and enablers of ACP perceived by physicians and other primary health care professionals	Cross-sectional Self-administered survey 117 GPs and 64 other HCWs N=181	• Perception that it is the GPs job to cure patients, that patients should initiate discussions were not barriers • GPs had no fear that discussing ACPs would interfere with their relationship with the patient Barriers for ACP discussions: • Lack of time • No electronic ACPs • Decreased interaction with patients near EOL • Patients' knowledge of illness diagnosis/prognosis/trajectory Facilitators for ACP discussions: • Long-term patient-physician relationship • Interprofessional role allocation regarding ACPs	• Survey originated from previous validated study and further developed on by GPs and HCWS • Open-ended questions included at the end of the questionnaire • 2 analysts coded all comments made • GPS in 3 different provinces enrolled • Large sample size (n=181)	• Considered patients older than 50 • Responder bias
Scholten et al. (2018) **Flanders, Belgium** **Advance Directive: Does the GP Know and Addresses What the Patient Wants? Advance Directive in Primary Care**[24]	To determine what barriers GPs and patients identify regarding ACP discussions	Cross-sectional 502 citizens and 117 GPs N = 619	• Most GPs make less than 5 ACPs a year • Individuals like to be in control of ACPs and initiate discussions Barriers for ACP discussions: • Lack of time • Lack of experience and knowledge • Complexity of ACP documents • Personal discomfort	• Large sample size • Considered well individuals not terminally ill • Citizens were over the age of 64, which is younger than similar previous studies conducted	• Not a validated survey • Responder bias • Survey only provided in Dutch
Wichmann et al. (2018) **Netherlands** **Advance care planning conversations with**	To determine GPs experiences with ACP discussions and the factors influencing these discussions	Semi-structured interviews N=17	• Mixed results regarding utilization of ACP guidelines • Easier to implement ACPs for cancer patients than other types of patients Barriers for ACP discussions: • Difficult topic to bring up	• Transcribed via an official agency • Constant comparative method used for data analysis • Participants had strong knowledge regarding ACPs	• GPs were recruited from an ACP training program, thus not representative of the wider population • Different interview methods used (face-to-face, or telephone)

palliative patients: looking through the GP's eyes	• Emotional impact on GP • Lack of time • Uncertainty of when to initiate conversation, especially if patients still being treated in the hospital • Anxious patients • GPs personal beliefs conflict with patients • Lack of communication between GPs and specialists	• Interviews conducted in Dutch • Various interview locations could cause confounders • Small sample size • Use of open-ended questions makes it difficult to analyze the results

Legend: ACP, Advance Care Planning. EOL, End of Life. GP, General Practitioner. HCW, Healthcare Worker.