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State of Advance Care Planning Research: A Descriptive Overview of Systematic Reviews

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Short title

A Descriptive Overview of ACP Research

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State of Advance Care Planning Research: A Descriptive Overview of Systematic Reviews

Abstract

Objective: To provide an overview of the current state of research of Advance Care Planning (ACP), highlighting most studied topics, publication time, quality of studies and reported outcomes, and to identify gaps to improve ACP receptivity, utilization, implementation, and outcomes.

Methods: Cochrane methodology for conducting overviews of systematic reviews. Study quality was assessed using a modified version of the AMSTAR tool. The following databases were searched from inception to April 2017: MEDLINE, EBM Reviews, Cochrane Reviews, CINAHL, Global Health, PsycINFO and EMBASE. Searches were supplemented with grey literature and manual searches.

Results: Eighty systematic reviews, covering 1662 single articles, show that ACP-related research focuses on nine main topics including: 1) ACP as part of end-of-life or palliative care interventions, 2) care decision making; 3) communication strategies; 4) factors influencing ACP implementation; 5) ACP for specific patient groups, 6) ACP effectiveness; 7) ACP experiences; 8) ACP cost; and 9) ACP outcome measures. The majority of this research was published since 2014, its quality ranges from moderate to low, and reports on documentation, concordance, preferences and resource utilization outcomes.

Significance of Results: Despite the surge of ACP research, there are major knowledge gaps about ACP initiation, timeliness, optimal content and impact due to the low quality and fragmentation of the available evidence. Research has mostly focused on discrete aspects within ACP instead of employing a holistic evaluative approach that takes into account its intricate working mechanisms, the effects of systems and contexts, as well as the impacts on multilevel stakeholders. Higher quality studies and innovative interventions are needed to develop effective ACP programs and address research gaps.

Keywords

Advance care planning, end-of-life care, palliative care, overview, systematic reviews

Introduction

The Institute of Medicine recommends the conduct of Advance Care Planning (ACP) to better align the services received by the individuals with their care goals and preferences (IOM (Institute of Medicine), 2014). As a result, stating end-of-life (EOL) preferences has become an important and internationally widespread process in recent years (Mullick, Martin, & Sallnow, 2013; Sabatino, 2010). ACP refers to ongoing discussions about shared decision-making in which patients (including residents of long-term care institutions and clients in community settings), their families, and healthcare providers reflect on the patient's goals, values, and beliefs in relation to their current and future medical care (Detering & Silveira, 2016; Sudore, Lum, et al., 2017). Ideally, this process should document patients' future health care choices so that this information follows them across different healthcare settings (Hickman, Hammes, Moss, & Tolle, 2005).

ACP is a complex intervention that involves multiple stakeholders interacting with each other and with the healthcare system. To be implemented successfully, it entails the breaking down of barriers against conversations about death and dying, and requires accurate and honest disclosure about prognosis, in order to increase receptivity or openness to receive ACP. The discussion itself needs to be culturally, linguistically, and emotionally tailored to patients and their families. These discussions can occur in different medical and non-medical settings. Different organizational contexts and disease conditions may give rise to a variety of implementation challenges. The eventual goal of ensuring that "people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (Sudore, Lum, et al., 2017), is influenced by all the above factors.

When appropriately conducted, ACP may benefit patients (increased autonomy, dignity, peace and intimacy at moment of death), their family (less intense grieving, less likelihood of developing psychiatric conditions), and the healthcare system more generally (decreased resource utilization and costs) (Lum, Sudore, & Bekelman, 2015). Despite these potential benefits, it is often difficult to engage patients and other stakeholders in these highly emotive conversations about life and mortality (Barclay, Blackhall, & Tulsky, 2007), and there is a lack of clear guidelines and uniformity in its implementation. Depending on the context, the concept and definition of ACP varies, may involve different legal status or require special legal documents (such as advance directives (AD), living wills or powers of attorney), and it is not always embedded into routine clinical care (Lovell & Yates, 2014). All these elements result in different conclusions regarding the effectiveness of ACP.

Several studies have tried to identify the factors that may act as barriers or facilitators for this process, taking the perspective of healthcare professionals, proxy decision-makers, and patients with various illnesses. These factors vary and may include finding the most appropriate setting and timing for these conversations, levels of diagnosing skills, length of relationships between healthcare professional and patient, discussion strategies, and educational and emotional support for patients, family members and professionals (De Vleminck et al., 2013; Jethwa & Onalaja, 2015; Lord, Livingston, & Cooper, 2015; Lund, Richardson, & May, 2015; van der Steen et al., 2014).

Demonstrating the wide variety of research on the topic, studies have focused on particular aspects of ACP, including the use of decision aids (Aslakson et al., 2015; Austin, Mohottige, Sudore, Smith, & Hanson, 2015; Butler, Ratner, McCreedy, Shippee,

& Kane, 2014), communication strategies (Bernacki, Block, & American College of Physicians High Value Care Task, 2014; Parry, Land, & Seymour, 2014; Walczak, Butow, Bu, & Clayton, 2016), the impact of different types of ACP and palliative care interventions (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Hall, Kolliakou, Petkova, Froggatt, & Higginson, 2011; Hickman, Keevern, & Hammes, 2015; Houben, Spruit, Groenen, Wouters, & Janssen, 2014), and most common outcomes to measure ACP (Lorenz et al., 2006; Luckett et al., 2014; Mularski et al., 2007). In fact, a recent study involving a Delphi panel of experts sought to provide an update about the most important outcomes related to ACP (Sudore, Heyland, et al., 2017).

Another area of interest related to ACP has focused on examinations of EOL and palliative care, where studies have concluded that ACP is an important element for these fields (Auriemma et al., 2014; Kirolos et al., 2014; Raymond et al., 2014; Wang & Chan, 2015). Additionally, the experiences and attitudes of different stakeholders implementing or receiving ACP have been studied (Fosse, Schaufel, Ruths, & Malterud, 2014; S. Johnson, Butow, Kerridge, & Tattersall, 2015; Ke, Huang, O'Connor, & Lee, 2015).

All these different aspects related to ACP have been analysed in a wide variety of original studies and systematic reviews (SRs). However, they have been studied in isolation, resulting in fragmented research and overlooked evidence. As highlighted in a recently proposed definition and framework, ACP is a complex intervention comprised of several aspects which should be integrated with each other (Sudore, Heyland, et al., 2017; Sudore, Lum, et al., 2017). There is currently no comprehensive document summarizing this growing body of research and comparing it with this recent ACP definition and framework. A systematic narrative overview (Grant & Booth, 2009) will integrate the

findings from SRs pertaining to ACP, in order to interpret and broaden its understanding including all the aspects that influence this process as available in the published literature.

The aim of this overview of SRs is to summarise the current state of research on ACP, bringing together seemingly disparate aspects into a holistic ACP concept, and to identify the most important knowledge gaps. We identified populations under study, countries where research has been conducted (to explore cultural influences on ACP), most studied ACP-related topics, research methodologies and quality of the studies, and most reviewed outcome measures. Additionally, we identified research and knowledge gaps in order to guide future research and funding efforts to improve ACP.

Methods

For this overview, we define ACP as the process involving discussions, usually close to the EOL, whereby patients state their preferences for future treatment (including proxy designation, place of care and of death) were they to become incapacitated (Sudore, Lum, et al., 2017). These discussions may or may not be documented, but it is essential that there is tangible proof that the discussions took place. Methods for this overview were developed based on criteria for conducting overviews of reviews in the Cochrane Handbook of Systematic Reviews of Interventions to ensure methodological rigor and minimize the risk of bias (Becker & Oxman, 2011).

Search strategies

We conducted literature searches between March 2016 and April 2017, through each of the following databases from their inception: MEDLINE, EBM Reviews and Cochrane

Reviews through OVID; CINAHL, Global Health and PsycINFO through EBSCO; and EMBASE. We developed three search strategies in collaboration with our medical librarian to maximize sensitivity and specificity for each search engine. Two main strings of terms were developed: one pertained to ACP and its related concepts and keywords, and the second string to the methodological filter for SRs, derived from the guidelines described in the Canadian Agency for Drugs and Technologies (CADTH)'s Database Search Filters and the Health Information Research Unit (HIRU)'s Search Strategies (Canadian Agency for Drugs and Technologies in Health (CADTH), 2016; Health Information Research Unit (HIRU), 2016). See Appendix A for the search terms used in each database. We also manually searched Google and Google Scholar to ensure the completeness of our overview. Additionally, we searched three grey literature databases: base-search.net, Opengrey.org and science.gov. References were managed using Endnote X7 (Clarivate Analytics, 2016).

Eligibility criteria

As per our definition, we included reviews with a primary focus on ACP – those that examined ACP or any of its related aspects such as its effectiveness or completion rates as defined by each study, barriers/facilitators, types of ACP tools used, decision aids, communication strategies, and economic impact, etc. We also included reviews that may not focus on ACP but may include ACP as one of the key outcomes or results.

We developed an *a priori* exclusion and inclusion criteria scheme (Table 1), and included SRs that mentioned Advance Medical Directives (AD), Do-Not-Resuscitate (DNR), Do-Not-Hospitalize (DNH), and Lasting Power of Attorney (LPA) as well as ACP, if they

describe that a discussion between patient and medical professional took place in any setting. Further, studies that covered concepts inherent in the definition of ACP such as EOL decision making, treatment preferences, surrogate decision-making, etc. are included.

[INSERT TABLE 1 ABOUT HERE]

In order to comprehensively cover the ACP literature, there were no restrictions on study designs, populations, settings or stakeholders involved in the discussions. No language, geographical, or publication date restrictions were applied.

Screening and selection of studies

Two authors (GJ & WS) independently screened titles, abstracts, and keywords to identify relevant studies for full-text review. Three authors (GJ, WS, AKV) independently screened full texts for final inclusion. Discrepancies were resolved through discussion and consensus.

Data extraction and critical appraisal of included studies

We developed a data extraction table which included: general information, topic of paper, PICO (population, interest, context, outcomes), methodology, results, and conclusions and future research (Appendix B).

Full data extraction of all the included studies was performed by the lead author (GJ). A second author (AKV) performed data extraction on a random sample of 20% of the included studies and results were compared for consistency. There were minimal

discrepancies (10%), which were resolved by discussion and reappraisal. The second author also reviewed the data extraction performed by the lead author for the remaining studies.

We assessed the quality of included SRs to evaluate their methodological rigor and strength of the evidence they provide, using a modified version of the AMSTAR tool, an 11-item checklist widely used to evaluate the methodological quality of mainly quantitative systematic reviews (for details, see Appendix C) (Shea et al., 2007). We modified this tool as described in Lou et al (2017) (Lou, Carstensen, Jorgensen, & Nielsen, 2017), where items 9 and 10 were adapted and excluded, respectively, to evaluate SRs that followed a narrative approach, and used qualitative or mixed methodologies.

Our adapted checklist contained ten items for a maximum score of 10. A review that adequately met all of the 10 criteria was considered to be of the highest quality. The quality rating was as follows: a score (out of 10 criteria) rating of 8 to 10 is considered as high quality, 4 to 7 as moderate quality and 3 or lower as low quality (Bashi, Karunanithi, Fatehi, Ding, & Walters, 2017). The quality scores were not used to exclude articles from our overview but to inform about the quality of the research and guide the interpretation of the findings (for details on the quality assessment for each SR, see Appendix C). Similar to the data extraction process, GJ performed quality assessment on all studies and AKV performed the same process on a random sample of 20% of the studies. There were no discrepancies. The second author also reviewed the quality appraisal performed by the lead author for the remaining articles.

Data analysis, synthesis and presentation

Data analysis was informed by the Framework Method involving thematic analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Mays & Pope, 1995; Ritchie & Lewis, 2003). Two reviewers (GJ & WS) performed the familiarization and coding stages with the articles derived from the manual search. This served to identify recurrent themes and main topics of the reviews in the literature, and to develop the working analytical framework displayed in the standardized extraction form in Microsoft Excel (Appendix B), which was used to categorize information along pre-determined categories. Through reflection and iteration, thematic categories were further refined to derive a final set of codes to interpret the results. The data are presented using a narrative, descriptive approach, typically used in cases where the research question dictates the inclusion of a wide range of research designs, including qualitative and/or quantitative findings (Gilissen et al., 2017). Additionally, research gaps were identified from the included studies and thematically organized, ensuring consistency with the rest of the presented results. Given the heterogeneity of the included studies, it was not possible to pool results or use meta-analytical approaches.

This work was based on publicly available literature and did not require ethics approval.

Results

Search results

Keyword searches on the electronic databases returned 259 articles and manual searches on Google and Google Scholar resulted in 59 articles. Grey literature searches resulted in

no additional articles. After deduplication, 250 papers were subjected to title and abstract screening. After this process, we excluded 115 articles and retrieved the full texts of the 135 remaining articles for full text screening, from which 72 were deemed appropriate for inclusion. The search update resulted in eight additional studies. Final analysis was performed on 80 SRs, which form the basis of this overview. The search results and details can be seen in the PRISMA flowchart in Figure 1 and for the list of excluded studies, please refer to Appendix D.

[INSERT FIGURE 1 ABOUT HERE]

Study characteristics

The table in Appendix E lists and provides the characteristics of the 80 included SRs. The number of single studies included in the SRs and therefore covered by our overview is 1662. From these, 316 studies were included in more than one SR. The majority of these studies were peer-reviewed journal articles, but the SRs also included guidelines or pathways, government organization reports, and book chapters. The most frequently included studies were the article describing the SUPPORT trial (in ten SRs) (The SUPPORT Principal Investigators, 1995), an article by Molloy et al. describing the implementation of an advance directive program in nursing homes (in 11 SRs) (Molloy et al., 2000), and an article by Morrison et al. explaining the effect of a social work intervention for ACP documentation (in 12 SRs) (Morrison et al., 2005).

A summary of the characteristics of the SRs included in this study can be found in Table 2. The majority (60%) of the SRs were published from 2014 and onwards. SRs utilized qualitative methodologies including narrative or descriptive synthesis, or thematic

analyses, due to the heterogeneity of their included studies. Ten of the 80 SRs reported meta-analyses, eight of them being performed only in a subset of their total included studies. Seventeen SRs explicitly performed risk of bias analysis, providing different levels of details and overall reporting high or unclear risk of biases.

[INSERT TABLE 2 ABOUT HERE]

The large majority of included SRs (95%) were of moderate to low methodological quality. Notably, none of the 80 included SRs satisfied the criterion about indicating the conflict of interest for each of their included studies, and only three provided a list or referenced the excluded studies, which accounted for the lower scores for the vast majority of SRs. Most studies included in the SRs come from high-income, Western countries, and more than half of all the SRs looked at patient populations only.

Systematic reviews' main topics

We identified nine main topics, under which the majority of the SRs were classified. These include: ACP as part of end-of-life or palliative care interventions, care decision making, communication strategies, factors influencing ACP implementation, ACP for specific patient groups, ACP effectiveness, ACP experiences, ACP cost, and ACP outcome measures. Given that a large number of reviews touched upon one or several topics, the primary topic of each review was utilised for categorization. Detailed elaboration of each main topic with the relevant number of reviews covered are provided in Table 3.

[INSERT TABLE 3 ABOUT HERE]

Four reviews were categorized under “others” as their main topics were educational interventions (Chung, Oczkowski, Hanvey, Mbuagbaw, & You, 2016; Durbin, Fish, Bachman, & Smith, 2010), the evaluation of a specific ACP program, the Provider Orders for Life Sustaining Treatments (POLST) (Hickman et al., 2015), and ACP policy impact (Zager & Yancy, 2011). Figure 2 provides a framework for the role of each topic within the concept of ACP.

[INSERT FIGURE 2 ABOUT HERE]

Most commonly studied interventions and outcome measures

In line with the most studied topics, the most commonly studied interventions were those aimed at improving EOL or palliative care (Hall et al., 2011; Kavalieratos et al., 2016; Khandelwal et al., 2015; Lorenz et al., 2008; Walling et al., 2008; Wickson-Griffiths, S., Ploeg, & McAiney, 2014). Then, several reviews focused on ACP interventions, either comparing different ACP formats (Austin et al., 2015; Dixon, Matosevic, & Knapp, 2015; Walczak et al., 2016), or looking at whether they impacted diverse outcomes (Baidoobonso, 2014; Brinkman-Stoppelenburg et al., 2014). Also, some studies reviewed specific types of ACP such as the POLST (Hickman et al., 2015), and the “Let me decide”, “Let me talk” or other ACP programs (Wickson-Griffiths et al., 2014). Some studies focused on specific aspects within our ACP definition, such as evaluating interventions that focused on ADs (Brinkman-Stoppelenburg et al., 2014; Houben et al., 2014), and DNR and DNH orders (Brinkman-Stoppelenburg et al., 2014). Several studies looked at interventions involving decision aids or decision-making (Aslakson et al., 2015; Jain et al., 2015; Sessanna & Jezewski, 2008; K. Song, Amatya, Voutier, & Khan, 2016),

communication or discussion strategies (Baidoobonso, 2014; Oczkowski, Chung, Hanvey, Mbuagbaw, & You, 2016; Walczak et al., 2016; Walling et al., 2008), and interventions focused on providing information or education to different stakeholders such as patients, carers, and healthcare providers (Durbin et al., 2010; Hanson, Tulskey, & Danis, 1997; Jezewski, Meeker, Sessanna, & Finnell, 2007; Patel, Sinuff, & Cook, 2004; Ramsaroop, Reid, & Adelman, 2007; Tamayo-Velazquez et al., 2010; Walczak et al., 2016).

Examples of outcomes to measure the effectiveness or quality of ACP in the SRs include:

- Presence of ACP/EOL discussions (with different stakeholders) (Hickman et al., 2015; Murray & Butow, 2016; Rahemi & Williams, 2016; Sanders, Robinson, & Block, 2016; Smith, Jaffray, & Ellis, 2013; K. Song et al., 2016; Sumalinog, Harrington, Dosani, & Hwang, 2016; Weathers et al., 2016);
- Completion outcomes: ACP document completion, or documentation of preferences (Baidoobonso, 2014; LoPresti, Dement, & Gold, 2016; Sumalinog et al., 2016; Wang & Chan, 2015; Weathers et al., 2016); AD use or AD completion rates (LoPresti et al., 2016; Ramsaroop et al., 2007; Sanders et al., 2016; Sumalinog et al., 2016; Wang & Chan, 2015; Weathers et al., 2016; Wicher & Meeker, 2012);
- Concordance outcomes: concordance between patients' and families' wishes (Baidoobonso, 2014; Ke et al., 2015; Martin, Hayes, Gregorevic, & Lim, 2016; Meeker & Jezewski, 2005); concordance of preferences with actual treatment (Murray & Butow, 2016);

- Preference outcomes: preferences for or use of life-prolonging measures (K. S. Johnson, Elbert-Avila, & Tulsky, 2005; LoPresti et al., 2016; Martin et al., 2016; Ramsaroop et al., 2007; Wicher & Meeker, 2012); preferred place of death (Martin et al., 2016; Rahemi & Williams, 2016);
- Healthcare/resource utilization outcomes: resource use (Weathers et al., 2016); hospitalization rates (Martin et al., 2016; Oliver et al., 2004; Weathers et al., 2016); number of days spent at hospital or ICU (Baidoobonso, 2014; Dixon et al., 2015; Khandelwal et al., 2015); ICU use (Baidoobonso, 2014; Khandelwal et al., 2015) hospice care/use (Baidoobonso, 2014; LoPresti et al., 2016; Rahemi & Williams, 2016; Wicher & Meeker, 2012); palliative care referrals (Martin et al., 2016; Oliver et al., 2004).
- Satisfaction with care outcomes (Murray & Butow, 2016; Weathers et al., 2016);

Additionally, a SR that reviewed the evidence about patients with chronic kidney disease (CKD) (Luckett et al., 2014) found that 110 measures were used, most commonly relating to patient and/or family preferences, attitudes and knowledge, and AD completion rates. Another SR (Biondo et al., 2016) found that documentation of patients' EOL treatment wishes was the most common outcome measure (in 76% of included its studies), followed by the occurrence of ACP/AD/EOL care (in 57% of its studies), and by healthcare resource utilization outcomes (in 39% of its studies). Patient-, family-, or healthcare professional-reported outcomes were less commonly measured (reported by 13%, 4%, and 20% of its studies, respectively). Concordance measures (e.g. dying in place of choice) were reported by 26% of the studies included in this review (Biondo et al., 2016).

ACP knowledge & research gaps, as presented in the included SRs

The studied SRs include in their analyses and mention several aspects that are either missing or provide insufficient knowledge regarding ACP.

First, differing legislations between countries and within states of countries, and differing terms used to describe the process and documents, hinder successful ACP processes (Smith et al., 2013). There is lack of research on promotion and implementation of AD and ACP, especially when taking into account the need to move from a hospital- to a community-based EOL care model (Wang & Chan, 2015).

Patients and caregivers tend to avoid discussions or documentation of EOL care, as they felt these “are connected to death and loss of hope” (Murray & Butow, 2016). Health professionals reported that the rigidity of using structured forms may leave out discussions about important issues that are not included in them, and the presence of various forms causes confusion and challenges when trying to explain them (Hickman et al., 2015; Ke et al., 2015).

Another gap refers to EOL discussions not occurring as much as they should. A low number of patients with primary malignant brain tumours had EOL discussions regarding treatment preferences, health care proxy, palliative care consultation, hospice discussion, and resuscitation wishes; when these discussions took place, many physicians were not aware of their patients’ EOL preferences (Sizoo et al., 2014; K. Song et al., 2016). Another study points to even lower numbers of discussions being held with frail older people, even though in most cases they wanted to have them (Sharp, Moran, Kuhn, & Barclay, 2013). As healthcare professionals fail to initiate the AD discussion, they lack

knowledge regarding what is important for their older patients' EOL care needs and preferences (Sessanna & Jezewski, 2008).

The SRs also mention limited evidence about the timeliness and initiation of ACP discussions. For example, for patients with dementia, there is limited and unclear evidence on how to best approach ACP and, in motor neuron disease, evidence varies between studies suggesting discussions should occur earlier and others suggesting they should occur at more advanced stages (Harrison Denning, Jones, & Sampson, 2011; Murray & Butow, 2016). An important barrier to these conversations is related to prognosis. In many cases, prognoses are inadequately documented and overestimated (Walling et al., 2008), and discussions are hindered due to unclear terminal diagnosis (Sharp et al., 2013). There is also a lack of information regarding the best setting for these discussions (S. Johnson et al., 2015).

Other gaps mentioned in the SRs include the variability in terms of the amount of information patients and caregivers want to know (K. S. Johnson et al., 2005). There is a need for enhanced EOL communication and for practical support, especially for family caregivers, who report unavailability from healthcare professionals (Lord et al., 2015). It is also difficult to elucidate what constitutes optimal content (Murray & Butow, 2016); the amount and type of preferences to be included, the level of detail the form should include, etc. is not well established and affects the process of decision-making.

There is little research regarding triggers for referral to palliative care services and inadequate evidence of EOL care and ACP in nursing homes (Dixon et al., 2015; Taylor, Heyland, & Taylor, 1999). The SRs also point to a lack of research about ACP for brain

tumour patients (K. Song et al., 2016), chronic heart failure and COPD (Siouta et al., 2016), and haemodialysis patients (Lim et al., 2016). There is also a need for interventions to reduce disparities among older adults from underrepresented groups given the great diversity of their EOL preferences (Rahemi & Williams, 2016).

There is little or no data on other ACP-related important outcomes such as confidence in decision-making, patients' sense of control and autonomy, actual use of healthcare services (including use of life-sustaining treatments), congruence of EOL treatments with advance care plans, impact on knowledge of ACP, EOL care preferences, satisfaction with healthcare, psychological and emotional effects of EOL discussions, as well as quality of life and quality of death (Houben et al., 2014; Jain et al., 2015; M. K. Song, 2004). Also, there is a lack of high quality evidence supporting reduced resource use and cost savings (Dixon et al., 2015; Taylor et al., 1999).

Discussion

There is a large body of research on ACP as evidenced by the high number of published SRs about the topic. Our broad conceptualization of ACP allowed us to uncover that the majority of this research (almost $\frac{3}{4}$ according to our findings) comes from studies focusing on the following five main topics: investigations on EOL or palliative care, EOL decision making or use of decision aids, EOL communication or discussion strategies, barriers and facilitators for ACP, and investigations regarding ACP for specific populations or settings. Additional main topics included experiences or perceptions towards ACP, ACP effectiveness, outcome measures and ACP cost or resource use.

The largest proportion of ACP-related research has been published since 2014, demonstrating the importance that this process has gained in clinical and EOL care during recent times. The majority of the research has been published in the United States, Canada and the United Kingdom following the interest and policies enacted in these countries, such as The Patient Self Determination Act (PSDA) of 1991 in the US, and the End of Life Care Strategy for England in 2008, just to give some examples. Hence, legislation provides a stimulus for research and accompanying funding as also evident in other research (Kinley, Froggatt, & Bennett, 2013; Oliver et al., 2004). With greater adoption of ACP outside of North America and Western Europe, greater attention should be paid to contextualizing current evidence for other settings, and to initiate research in these countries.

One striking feature revealed by the SRs is the heterogeneity and low quality of included studies. Almost half of the SRs had included studies with more than one methodology, and even in the one-third that included only quantitative studies, most were still too heterogeneous to allow pooling results. Additionally, not only were the studies included in the SRs of generally poor methodological quality, but also the SRs themselves were mostly of moderate to low quality.

Comparing the most recurrent ACP outcomes we found in the published SRs against a recent organizing framework of ACP outcomes based on a Delphi panel of ACP experts (Sudore, Heyland, et al., 2017), brings forth interesting results. On the one hand, several important outcomes present in the literature coincide with the opinions of experts: e.g. care received being consistent with goals, holding the discussion about values and care preferences with patient, surrogates and clinicians, and the documentation of these

preferences. On the other hand, there are also discrepancies. While experts placed a lot of importance for outcomes regarding ACP documentation being included in the medical records and easily accessible, this outcome is not currently studied in our included SRs. Conversely, in the literature we found outcomes such as hospitalization and ICU use, healthcare expenditures, hospice care use, etc., being consistently studied, while experts gave overall care utilization outcomes lower ratings of importance. Additional outcomes commonly present in the literature include satisfaction with care and concordance between patients' and families' wishes, which were also given a lower ranking by experts, and palliative care referrals, which was not included as measure for successful ACP by experts. A possible explanation for this discrepancy could be that the opinion of experts does not necessarily take into account what is important for other stakeholders, such as patients, family caregivers or healthcare administrators. As a result, it is important to highlight that the outcomes that ranked lower according the panel of experts, does not mean that they are not important outcomes to measure ACP. The fact that they have been consistently studied in the literature should be an indication they may be important outcomes for the other stakeholders mentioned above, and therefore be taken into account as a measure of ACP success and funding allocation.

Most of the published research focuses on discrete, specific events within ACP, as opposed to seeing it as a complex intervention and a holistic program. Since ACP is a continuous, iterative process involving multiple stakeholders and phases, usually across various settings, evaluations or interventions about only specific parts of the process (i.e. EOL decision-making, communication interventions, education and training, completion of documents, cost evaluations) may not result in improvements or accurate

representation of the process as a whole. As shown in other studies, a “whole-system” approach to ACP may provide better insights and improve outcomes for patients, family caregivers and health system (Detering, Hancock, Reade, & Silvester, 2010; Luckett et al., 2014). Additionally, in many studies, ACP is embedded as part of a larger EOL or palliative care program. In such situations, it is difficult to interpret the results regarding ACP and it is unclear whether the outcomes are driven by ACP or other parts of the program. Greater accuracy and transparency in reporting is warranted.

One of the most important messages coming from the SRs is the need for further research at different levels, both in its comprehensiveness as well as in its quality. The apparent reluctance from the general public to hold ACP conversations is a result of confusing legislation and documentation, combined with a lack of promotion of ACP, especially in the community. There is a clear need to streamline policies and to deploy public awareness campaigns, in order to educate the public on ACP and to normalize conversations about death. This should increase ACP receptivity at a societal level. Additionally, there should be enhanced training for health professionals on EOL communication and diagnosing skills so that they can support patients and their families when making decisions and at an emotional level. This should also improve ACP receptivity in addition to facilitating ACP implementation and utilization.

There is clearly a lack of knowledge regarding the best timing, setting and content for holding optimal ACP discussions. In order to further improve ACP implementation, research should focus on elucidating when to initiate these conversations and the amount of information patients and their families want to know, especially for different disease groups, as needs and decisions may be different from one patient group to another. Also,

research on outcomes such as congruence between ACP and received treatment, satisfaction/emotional/quality of life outcomes and resource use/cost saving outcomes should be prioritized to clarify ACP's real impact.

Higher quality and more diverse approaches are needed to explore specific research questions. For example, complex evaluation research (Craig et al., 2008), which has the capacity of evaluating interventions containing several interacting components, could be implemented for evaluating ACP effectiveness, as ACP is a form of complex intervention. Additionally, future work could require applying implementation science frameworks to address the gaps described above to improve the implementation of ACP programmes. However, as a result of the current research gaps and low quality evidence, overarching best practices cannot be provided.

There are some strengths and limitations to this overview. To our knowledge, this is the first study reviewing the state of research regarding ACP as a comprehensive process, without restrictions of populations, settings, and methodologies. Our main strength is the comprehensive ACP definition we adopted, which allowed us to include explicit ACP research, as well as conceptually relevant ACP aspects regardless of the presence of the "ACP" term itself. This should also ameliorate an inevitable systematic review limitation, namely that our search strategy might not have captured all available evidence. Our focus on SRs may have excluded other research that might potentially provide important insights into the conduct of the ACP process. However, we included systematic reviews in order to have a minimum standard of methodological and scientific quality of included studies.

In conclusion, ACP has gained much importance in EOL care in the past decade as reflected in the amount of research about this topic. Despite the evident surge in ACP research, there are still many gaps and given the low quality of the available evidence, it is not yet possible to provide unequivocal best practices that apply to all populations and settings. Research has mostly focused on discrete aspects within ACP (such as the ones mentioned above, namely preference documentation, discussion or communication strategies, decision aids for decision making, surrogate experiences, etc.) instead of looking at ACP in a holistic way, in which its different parts rely on one another and include many stakeholders, multiple settings and different stages. Higher quality and more diverse approaches, such as complex evaluation research, in different countries are needed to explore specific research questions. Only in this way we will be able to develop effective ACP programs based on reliable evidence to improve the quality of palliative and EOL care.

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The authors declare no conflict of interest with respect to the research, authorship and/or publication of this article.

Authorship

GJ, WST and JC contributed to the concept and design of this work. GJ, AKV and WST worked on acquiring, analyzing and interpreting the data, and on drafting the manuscript. CKL and AH provided substantial revisions to the manuscript. All authors approved the final version of this manuscript.

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Tables

Table 1: Inclusion and exclusion criteria

	Include	Exclude
Study Type	<ul style="list-style-type: none"> Systematic reviews (SRs) that (1) have been defined by the authors to be a systematic review within title, abstract, or text; and/or that (2) present evidence from the description of the methods that systematic review principles had been utilised in searching and appraising the evidence. {Black, 2011 #300} 	<ul style="list-style-type: none"> Articles that are not systematic reviews, including: <ul style="list-style-type: none"> Original studies Discussion pieces Opinions Editorials Narrative reviews Critical reviews
Population	<ul style="list-style-type: none"> Adult patients (healthy or with any disease/condition) Caregivers (formal or informal, relatives, spouses, etc.) Healthcare professionals (physicians, nurses, social workers, etc.) Healthcare managers/administrators 	<ul style="list-style-type: none"> Paediatric populations (under 18 years of age)
Study Design	<ul style="list-style-type: none"> Qualitative studies Quantitative studies Mixed 	<ul style="list-style-type: none"> No restrictions
Study Setting	<ul style="list-style-type: none"> Acute care settings Intermediate/Long-term care settings Community settings, including patients' homes Inpatient/Outpatient settings 	<ul style="list-style-type: none"> No restrictions
Study focus	<ul style="list-style-type: none"> ACP as primary topic of interest Any subtopic of interest within ACP including (but not limited to) effectiveness, barriers/facilitators, completion rates, types of ACP, communication strategies, decision-aids, cost effectiveness, etc. Palliative and/or end-of-life studies for which ACP is a key indicator or outcome Studies that covered concepts inherent in the definition of ACP such as end-of-life decision making, treatment preferences, and surrogate decision making 	<ul style="list-style-type: none"> Studies focusing only on advanced medical directives, do not resuscitate orders, lasting powers of attorney, or any other medical planning tool if an ACP discussion was not described or held Studies focused only on increasing the completion rates of advance medical directives with no reference to an ACP related discussion Studies focused on advance treatment directives for individuals diagnosed with mental illnesses
Publication status	<ul style="list-style-type: none"> All languages Peer-reviewed journal publications Grey literature 	<ul style="list-style-type: none"> No language or time restrictions

Source: Author's analysis

Table 2: Summary of systematic reviews' characteristics

Publication year	1994-2000	5% (4)
	2001-2007	14% (11)
	2008-2013	21% (17)
	2014-present	60% (48)
Methodologies of SRs*	Descriptive/narrative/qualitative synthesis	40% (32)
	Thematic/content analysis; category development; outcome groupings	19% (15)
	Other	9% (7)
	Not reported	21% (17)
	Meta-analyses	13% (10)
	Risk of bias analysis	21% (17)
Methodologies of studies included in SRs	Combination	44% (35)
	Only quantitative	39% (31)
	Only qualitative	8% (6)
	Only SRs	3% (2)
	Not reported/Guidelines or measures	8% (6)
Methodological quality of SRs (out of 10 pts.)	High (8-10)	5% (4)
	Moderate (4-7)	65% (52)
	Low (3-0)	30% (24)
Countries of articles included in SRs*	USA	79% (63)
	Canada	44% (35)
	Australia	38% (30)
	UK	35% (28)
	Netherlands	18% (14)
	Asian countries	28% (22)
	Only articles from 1 country	21% (17)
Populations studied in SRs	Patients only	56% (45)
	Health professionals only	5% (4)
	Surrogate decision-maker only	1% (1)
	Mixed populations	28% (22)
	Not specified	10% (8)

Source: Authors' calculations; *non-exclusive categories

Table 3: Main topics and number of systematic reviews in each

Main topic of SR ¹	Definition	# of SRs (%)	Refs.
1. ACP as part of EOL/Palliative care intervention	Studies evaluating or investigating EOL or palliative care in general, which included ACP as an important outcome or aspect under study	15 (19%)	(Auriemma et al., 2014; Hall et al., 2011; Hanson et al., 1997; Kavalieratos et al., 2016; Kinley et al., 2013; LoPresti et al., 2016; Lorenz et al., 2008; Mpinga, Chastonay, & Rapin, 2006; Oliver et al., 2004; Qaseem et al., 2008; Rahemi & Williams, 2016; Raymond et al., 2014; Siouta et al., 2016; Sizoo et al., 2014; Wang & Chan, 2015)
2. Decision aids or decision-making	Studies whose main focus was to investigate decision aids' efficacy, or how decisions were made at EOL when deciding treatment preferences, or looking at surrogate decision-making	12 (15%)	(Aslakson et al., 2015; Austin et al., 2015; Gorman, Ahern, Wiseman, & Skrobik, 2005; Jain et al., 2015; Kelly, Rid, & Wendler, 2012; Lord et al., 2015; Meeker & Jezewski, 2005; O'Connor et al., 1999; Oczkowski et al., 2016; Petriwskyj et al., 2014; Sessanna & Jezewski, 2008; Wendler & Rid, 2011)
3. ACP research or implementation for specific patient groups or settings	Studies investigating the impact of ACP specifically for certain patient groups (cancer patients, older adults, etc.) or settings (nursing homes, general practice, etc.)	10 (13%)	(Harrison Dening et al., 2011; Lim et al., 2016; Luckett et al., 2014; Martin et al., 2016; Murray & Butow, 2016; Smith et al., 2013; K. Song et al., 2016; Sumalinog et al., 2016; Weathers et al., 2016; Wickson-Griffiths et al., 2014)
4. Facilitators and barriers to ACP implementation	Studies whose main focus was to examine facilitators and/or barriers to ACP implementation, including organisational aspects, initiation of discussions, completion of documentation, etc.	10 (13%)	(De Vleminck et al., 2013; Frost, Cook, Heyland, & Fowler, 2011; Gilissen et al., 2017; K. S. Johnson et al., 2005; Lovell & Yates, 2014; Lund et al., 2015; Ramsaroop et al., 2007; Sanders et al., 2016; van der Steen et al., 2014; Wicher & Meeker, 2012)
5. Communication or discussion strategies	Studies that focused on aspects related to communication or discussion strategies (improving communication skills, effective discussion approaches, etc.) to improve ACP, increase documentation rates, etc.	10 (13%)	(Baidoobonso, 2014; Layson et al., 1994; Lewis, Cardona-Morrell, Ong, Trankle, & Hillman, 2016; Ostherr, Killoran, Shegog, & Bruera, 2016; Parry et al., 2014; Schofield, Carey, Love, Nehill, & Wein, 2006; Sharp et al., 2013; M. K. Song, 2004; Walczak et al., 2016; Walling et al., 2008)
6. Experiences, perceptions or attitudes towards ACP	Studies that examined the experiences towards the ACP process, its discussions and its effects for different stakeholders	6 (8%)	(Fosse et al., 2014; S. Johnson et al., 2015; Ke et al., 2015; Kim, Deatrick, & Ulrich, 2017; Lee, Hinderer, & Kehl, 2014; Tong et al., 2014)
7. Effectiveness of ACP	Studies investigating ACP effectiveness, looking at different ACP interventions or utilizing a variety of outcome measures	6 (8%)	(Brinkman-Stoppelenburg et al., 2014; Houben et al., 2014; Jezewski et al., 2007; Patel et al., 2004; Robinson et al., 2012; Tamayo-Velazquez et al., 2010)
8. Outcome measures for ACP	Studies that investigated what measures are used to evaluate ACP	3 (4%)	(Biondo et al., 2016; Lorenz et al., 2006; Mularski et al., 2007)
9. Cost or resource use	Studies that specifically tried to evaluate how ACP affected resource use (in terms of hospitalizations or ICU use, for example) and its cost impact	4 (5%)	(Dixon et al., 2015; Khandelwal et al., 2015; Klingler, In der Schmitt, & Marckmann, 2016; Taylor et al., 1999)

Source: Authors' calculations

¹Four systematic reviews were classified as having "Other" main topics

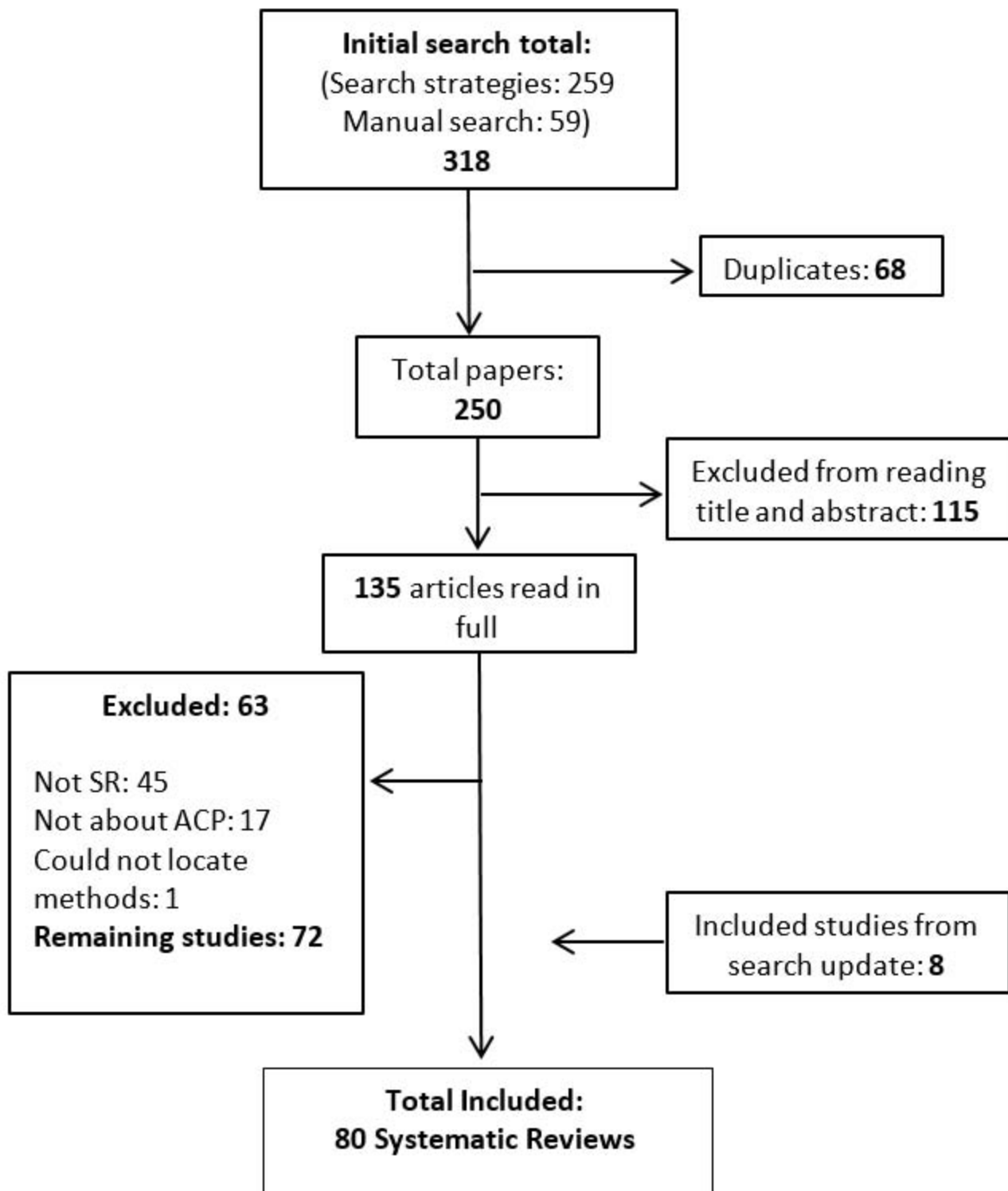
Figures List

Figure 1: PRISMA diagram of search results

Notes: SR: Systematic reviews

Figure 2: Systematic Reviews' main topics¹ (in parenthesis, number of SRs per topic)

Notes: Source: Authors' analysis; ¹Four systematic reviews were classified as having "Other" main topics



Contextual Factors



Implementation



Outcomes

EOL/Palliative Care
(15)

Experiences/
Attitudes towards
ACP (6)

ACP Research/Implementation for
different populations and settings (10)

Barriers and Facilitators (10)

ACP

Communication and
Discussions (10)

Decision making/
Decision aids (12)

ACP Measures (3)

Effectiveness (6)

Cost/Resource Use (4)