Barriers to Advance Care Planning implementation in healthcare: An umbrella review

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Abstract

Background: Advance Care Planning refers to a process of discussions between professionals, families and patients allowing individuals to define their care and treatment preferences. Understanding the barriers to Advance Care Planning is the first step on the way to overcoming them and to improving person-centred care and attention.

Aims: To identify the barriers perceived by professionals, patients and family members when implementing Advance Care Planning in a clinical context and to analyse the methodological quality of the evidence.

Methods: An umbrella review guided by Joanna Briggs Institute and a literature review in accordance with PRISMA 2015. Data were obtained from MEDLINE, Cochrane Library, Joanna Briggs Institute, CINAHL, Scopus and EMBASE in November 2018.

Results: Fourteen systematic reviews published between 2013 and 2017 were included. The main barriers reported by the professionals were: lack of knowledge and skills to carry out Advance Care Planning, and a certain fear of starting conversations about Advance Care Planning (and a lack of time). Patients and family members considered that the main barriers were: fear of discussing their relative's end of life; lack of ability to carry out Advance Care Planning; and not knowing who was responsible for initiating conversations about Advance Care Planning.

Linking Evidence to Action: Nursing have an important role to detect these barriers and promote changes in clinical settings aimed at respecting the wishes and wills of the patients.

Keywords: Advance directives; advance care planning; umbrella review; barriers; ethics

Introduction

In recent decades, scientific and technological advances in the health field have permitted the development of new therapeutic measures which have improved people's quality of life and increased survival rates (Arimany-Manso et al., 2017). This process has meant that diseases once seen as incurable are now considered chronic; inevitably, however, it has also pushed up spending in most health systems in developed countries. The need to manage the economic impact jeopardizes basic aspects of quality care and the model of healthcare humanization and person-centred care (Mahon, 2011). Another unavoidable consequence of applying technology to healthcare has been the emergence of ethical conflicts, particularly in the field of end-of-life care (Brown, 2003). Professionals have witnessed the extent to which technological capabilities can either save lives or prolong human suffering, launching the debate on which ethical criteria underpin decisions to limit human life support treatments (Arimany-Manso et al., 2017; Mahon, 2011; Brown, 2003; Sabatino, 2010).

In the late 1980s, the United States government promoted the Patient Self-Determination Act (PSDA), aimed at increasing sick people's decision-making by means of advance directives (Mahon, 2011; Sabatino, 2010; Rietjens et al., 2017; Stein, & Finberg, 2013). Nevertheless, the results of the SUPPORT study carried out between

1989 and 1994 showed that neither the law nor the intervention implemented in the study had succeeded in improving the way in which decisions were made at the end of life, nor had there been an increase in the fulfilment of the advance directives given by patients (Sabatino, 2010; Stein, & Fineberg, 2013). This situation led to the creation of Advance Care Planning(ACP), a deliberative, continuous and revisable process between professionals, families and patients designed to allow patients to define their care and treatment preferences (Stein, & Fineberg, 2013; Luckett et al., 2015; Dingfield, & Kayser, 2017; Houben et al., 2014).

At the end of the nineteen 1990s, a similar initiative was launched in Europe to protect the bioethical principle of respect for patients' autonomy, through the Convention for the Protection of Human Rights and the Dignity of the Human Being in the Biomedical field, also known as the "Oviedo Convention" (Arimany-Manso et al., 2017; Mahon, 2011; Stein, & Fineberg, 2013; Spacey, Scammell, & Board, 2018).

All these plans constituted a specific regulatory framework aimed at guaranteeing the respect of patients' rights in health-related decision-making processes. In recent years, substantial progress has been made regarding guidelines and policies to protect the principle of patient autonomy. Despite these improvements, problems arising in clinical environments have highlighted the need to analyse specific aspects of the implementation of these wills. Some studies have already pointed to difficulties or barriers faced by professionals, patients and family members that would explain why clinical decisions have not considered or carried out patients’ advance directives in certain clinical situations (Luckett et al., 2015; Boddy et al., 2013; De Vleminck et al, 2013; Beck et al., 2017; Simon, & Raffin Bouchal, 2016): barriers such as the staff’s lack of skills in managing advance directives, certain beliefs or prejudices, or previous negative experiences in relation to decisions at the end of patients' lives. All these issues hinder the participation of people in decisions regarding their health(Butteworth, 2003; Fanta, & Tyler, 2017; Kirmse, 1998).

Examining these barriers would allow the development of preventive or decisive measures that would encourage the implementation of patients' advance directives. The advance directive document itself and prior discussions of ACP emerge as key factors. For these reasons, the present study posed the following research question: what barriers do health professionals, patients and family members and/or caregivers report regarding appropriate ACP implementation in healthcare centres?

Bringing together evidence from previous research, this study set itself two main aims: to identify the barriers perceived by professionals, patients and family members; and to evaluate the methodological quality of the reviews published on the subject.

Methods

Design

An umbrella review was carried out following the guidelines of the Joanna Briggs Institute (JBI) (The Joanna Briggs Institute, 2014; Aromataris et al., 2015) and PRISMA on systematic reviews (Liberati et al., 2009). Our review was an Umbrella Review of qualitative evidence (Grant, Booth, & Centre, 2009): based on the definition given by the Joanna Briggs Institute (Aromataris et al., 2014), only meta-syntheses and systematic reviews of qualitative and quantitative studies without meta-analysis were considered.

A structured question was formulated seeking scientific evidence on the subject in PICo format, and the Joanna Briggs Institute's eligibility criteria were applied.

To contextualize the study, the "ACP" search terms were based on the definition of Advance Care Planning (ACP) published in 2017 by The European Association for Palliative Care (Rietjens et al., 2017). The definition of health service barriers proposed by Grol et al. was adopted for the concept of "barriers", i.e., barriers relating to health professionals, the social context and the organizational context (Wensing, 2007; Working Group on Implementation of GPC "Originally in Spanish", 2009).

Inclusion and Exclusion Criteria

Inclusion criteria were: qualitative and quantitative studies that included more than two databases in their literature search. Studies that analysed existing barriers to ACP implementation and the opinions of health professionals, patients and family members, without distinguishing between the type of disease or diagnosis, were also included.

The exclusion criteria were: narrative reviews, studies focusing on ACP in paediatrics, and reviews in a language other than English or Spanish.

Table 1 shows the inclusion criteria based on the type of study and the PICo question adapted to the Umbrella Review (Population, Phenomenon of interest and Context) (Aromataris et al., 2014).

Search Strategy

The search was performed in the MEDLINE, The Cochrane Library, Joanna Briggs, CINAHL, Scopus and EMBASE databases in 31th of November of 2018. The AND and OR booleans were used to combine the keywords. The search strategy was adapted according to the different databases consulted and the bibliographical references of the relevant reviews were revised to identify possible studies for inclusion. Table 2 illustrates the search strategies followed.

The search results were entered in the Mendeley Software. Subsequently, all titles and abstracts were examined following PRISMA guidelines to exclude reviews that failed to meet the established requirements. Potentially relevant texts were then retrieved and a full text review was carried out. The selection process was carried out independently by two authors (SPM, MB), and later supervised by a third reviewer (AFP) who also intervened in case of disagreement.

Data Extraction

The data extraction form based on JBI guidelines for data extraction in an Umbrella Review (The Joanna Briggs Institute, 2014) was used and the most important information in the studies included was compiled. The information collected from the reviews comprised: name of the study, author, year, objective, participants, context, description of the intervention or phenomenon of interest, number of databases used, period of years covered by the studies included, number and type of studies, country of origin of the reviews, methodological quality of the study and instrument used to assess it, method of analysis and findings. The categorizing of the information is detailed in Figure 2 below (information categorization process).

Quality Assessment

The Methodology for JBI Umbrella Reviews was followed (The Joanna Briggs Institute, 2014; Aromataris, 2014). Three authors (SPM, ABA, AFP) assessed the methodological quality of the reviews for inclusion using the JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (The Joanna Briggs Institute, 2017). This tool serves as a guide to assess the reliability of the included studies using a checklist consisting of 11 decisive questions (Q1-Q11). Each question must be answered "yes", "no", "uncertain" or "not applicable" (The Joanna Briggs Institute, 2017). The results of this evaluation indicate each review’s level of quality and are presented in the JBI-URARI data synthesis table (The Joanna Briggs Institute, 2014).

To create a classification based on these quality results, an ad-hoc criterion was incorporated where by a score of one point was assigned to a “yes” answer and zero was attributed to the rest of the options. The% was calculated on the basis that 11 positive answers represented 100%.

Data Analysis

Findings were summarized in descriptive tables presenting the information obtained from each review included (Tables 3 and 4). The data extracted from the tables were shown using a bubble diagram created using the Microsoft® Office Excel program. These figures show information in three dimensions: (1) the X axis shows the conclusions obtained by the reviews’ authors, divided into three types of barriers (health professionals, social context and organizational context); (2) the Y axis illustrates each study’s methodological quality obtained using the JBI-URARI tool (The Joanna Briggs Institute, 2014), and the bubble’s size depicts the number of individual studies included in each review: the larger the size, the larger the number of studies included.

Results

Four hundred and forty-two records were initially obtained from the databases. After discarding duplicates and selecting titles and abstracts, 354 were excluded, leaving 88 articles that were analysed full-text. Of these, 71 were excluded for failing to meet the inclusion criteria or the objective of the Umbrella Review. Seventeen reviews met the inclusion criteria, although seven were eliminated because they provided more information on facilitators than on perceived barriers regarding ACP implementation. Four articles were added to the remaining 10 (Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014), as they met the established inclusion criteria and were obtained by searching the lists of bibliographic references included in the reviews already selected. The 14 studies finally obtained (Lewis et al., 2015; Sharp et al., 2013; De Vleminck, et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans, Moll van Charante, & Willems, 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian, et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett, et al., 2014) reported results on the barriers to ACP implementation identified (Fig. 3).

Characteristics of Included Studies

Fourteen systematic reviews, embracing a total of 338 studies, were accepted for critical evaluation. All studies were published between the years 2013 and 2017. Most reviews were conducted by authors from Australia (Lewis et al., 2016; Lovell, & Yates, 2014; Johnson et al., 2016; Luckett et al., 2014) and the Netherlands (Glaudemans, Moll, & Willems, 2015; Shields, et al., 2014; Jabbarian et al., 2017; Van Der Steen, 2014). The main context addressed in seven reviews was end-of-life ACP (Lewis et al., 2016; Sharp et al., 2013; De Vleminck et al., 2013; Lovell, & Yates, 2014; Johnson et al., 2016; Van Der Steen et al., 2014; Luckett et al., 2014). The populations most represented in the studies were patients (Lewis et al., 2016; Sharp et al., 2013; Lovell, & Yates, 2014; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett et al., 2014) and health professionals (Lewis et al., 2016; Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Glaudemans, Moll, & Willems, 2015;Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett et al., 2014).

The methodological quality of the reviews included, according to the JBI Critical Appraisal Checklist (The Joanna Briggs Institute, 2017), ranged from 64% for the lowest quality to 91% for the highest quality (Table 5.). Four (Lewis et al., 2016; Lovell, & Yates, 2014; Mignani et al., 2017; Jabbarian et al., 2017) out of the 14 reviews answered 91% of the total number of questions (Q1-Q11) scoring a "YES" for the following items: adequacy of the search strategy and inclusion criteria, instrument of assessment of methodological quality, minimization of risk of bias and useful results for new studies.

In the same line, seven (Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Glaudemans, Moll, & Willems, 2015; Flo et al., 2016; Johnson et al., 2016; Van Der Steen et al., 2014) of the 14 reviews scored between 73% and 82%. Regarding the items in the evaluation grid, all reviews included (Lewis et al., 2016; Sharp et al., 2013; De Vleminck et al, 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans, Moll, & Willemns, 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shileds et al., 2014; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett et al., 2014) obtained a favourable answer in Q2, Q4, Q8, Q10 and Q11relating to: the suitability of the databases consulted and inclusion criteria, data synthesis, and useful recommendations and results for new research projects.

Outcome Analysis

1. Perceptions of nursing and medical professionals

Barriers relating to health professionals

When analysing the difficulties or barriers experienced by professionals, there seems to be a consensus that professionals' own lack of knowledge and specific skills for managing ACP represents a major obstacle to the implementation of the ACP. Seven of the fourteen reviews indicated that nursing and medical professionals reported a lack of knowledge and skills for managing ACP (Lewis et al., 2016; De Vleminck et al., 2013; Ke et al., 2015; Flo et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Luckett et al, 2014). One study found that nurses considered that they had little autonomy for conducting ACP (Johnson et al., 2016). According to De Vleminck et al., knowledge on how to involve patients in the performance of ACP is lacking, and professionals themselves note their difficulties in increasing the population's low participation in ACP (Table 3). The conclusions reached by these studies (with a methodological quality of 60%) were that the main barrier relating to health professionals was professionals' inexperience and lack of knowledge (Lewis et al., 2016; De Vleminck et al., 2013; Ke et al., 2015; Flo et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Luckett et al., 2014).

Barriers relating to social context

The appropriate clinical context for introducing advance directives and ACP is a complex question due to the patient's vulnerability and, in some cases, the uncertainty of the prognosis. Four reviews reported that health professionals did not know who was responsible for beginning ACP conversations, and expected patients to take the initiative (Ke et al., 2015; Lovell, & Yates, 2014; Johnson et al., 2016; Jabbarian et al., 2017). In addition, professionals said they feared depriving patients of hope by undertaking these conversations (Lewis et al., 2016; Flo et al., 2016; Johnson et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Luckett, et al., 2014) and that they did not know what their needs were (Glaudemans, Moll, & Willems, 2015). These views were reflected in an opinion study gathered in the review of Glaudemans et al. (2015), according to which 69% of doctors reported initiating conversations about ACP with patients with terminal illness, 12% indicated that they had never talked about end of life with their patients and 56% only talked about Cardiopulmonary Resuscitation (CPR) preferences when circumstances so required (Table 3).Two other notable aspects were uncertainty of prognosis (Lewis et al., 2016; Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Glaudemans et al., 2015; Johnson et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014) and the patient's cognitive state (Lewis et al., 2016; Sharp et al., 2013; Ke et al., 2015). According to Jabbarian et al., diseases sometimes follow an unpredictable course and prognosis is difficult (Table 3) Ke et al. consider it essential to analyse the likely course, together with the patient's cognitive state, prior to conducting ACP (Table 3). Most reviews, with a methodological quality of 60% (Fig. 3), reported that the main barriers relating to the social context included professionals' fears of depriving patients of hope (Lewis et al., 2016; Flo et al., 2016; Johnson et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Luckett et al., 2014), added to the uncertainty about when to start such conversations (Lewis et al., 2016; Sharp et al., 2013; De Vleminck et al., 2013; Glaudemans et al., 2015; Johnson et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van der Steen et al., 2014).

Barriers relating to the organizational context

All 14 reviews considered in this Umbrella review indicated that professionals attributed implementation difficulties to lack of sufficient time to start discussing ACP (Lewis et al., 2014; Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans et al., 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van De Steen et al., 2014; Luckett et al., 2014). Other barriers mentioned were lack of privacy (Lovell, & Yates, 2014; Johnson et al., 2016), lack of support from organizations for implementing ACP (Flo et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian et al., 2017), lack of continuity in the care of patients who make an ACP (Sharp et al., 2013; Jabbarian et al., 2017), hard-to-understand, non-standardized terminology(Ke et al., 2015), lack of collaboration between Primary Care and Hospital Care (De Vleminck et al., 2013), difficulty of access to computerized records (Lewis et al., 2016; Ke et al., 2015; Flo et al., 2016; Johnson et al., 2016; Shields et al., 2014; Lund, Richardson, & May, 2015), the legal implications of ACP (Lovell, & Yates, 2014; Flo et al., 2016), staff shortages, staff rotation (Sharp et al., 2013; De Vleminck et al., 2013; Flo et al., 2016) combining ACP with their other clinical and organizational commitments (Glaudemans et al., 2015; Lund, Richardson, & May, 2015). As shown in Fig.4, the "lack of time" barrier corresponds to the largest bubble in the diagram as it was found in all the studies included, with a methodological quality from 60% to 90%.

(Please insert Figure 4)

2. Perceptions of patients and family members

Barriers relating to health professionals

Four reviews indicated that patients were unaware of the person in charge of initiating ACP discussions, although they preferred that person to be the professional "who best knew them" (Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Luckett et al., 2014). Glaudemans et al. reported that only 15% of seniors had talked about ACP with their physician and 14% to 35% of patients with chronic diseases had discussed end-of-life preferences with their physician and/or nurse (Table 3). Another review signalled the obstacle of some patients’ unwillingness to discuss end-of-life issues with their attending professional (Mignani et al., 2017). Four of the 14 reviews (Lewis et al., 2015; Sharp et al., 2013; De Vleminck, et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans, Moll van Charante, & Willems, 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian, et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett, et al., 2014), with a methodological quality from 60% to 80%, considered that the main barrier relating to health professionals was that patients preferred their physician or nurse to initiate ACP discussions (Fig.5).

Barriers relating to the social context

Five reviews showed that patients presented fears of death (Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Flo et al., 2016; Van Der Steen et al., 2014) and that relatives expressed feelings of fear when initiating discussions about end-of-life (Sharp et al., 2013; Ke et al., 2015; Johnson et al., 2016; Mignani et al., 2017; Van Der Steen et al., 2014) attributed to the social taboo of death. According to Van der Steen et al., patients reported feelings of "guilt" or "not being ready" because they considered it difficult to discuss "such an unpleasant" issue, a situation that was also highlighted by family members (Table 3). In the same way, the review study by Sharp et al. (2013), indicated that elderly people were not willing to talk about the end of life and delegated the responsibility to their relatives, their referring physician, or left it "in God’s hands"(Table 3). The studies also indicated the following barriers: lack of patients’ knowledge of ACP (Ke et al., 2015; Johnson et al., 2016), uncertainty of prognosis (Mignani et al., 2017) and cultural factors impeding discussion of these preferences (Van

Der Steen et al., 2014). The results of five reviews revealed that fear on the part of patients and family members represented an important social context-related barrier to ACP implementation (Sharp et al., 2013; Ke et al., 2015; Johnson et al., 2016; Mignani et al., 2017; Van Der Steen et al., 2014). These reviews, presented a methodological quality of 80% (Fig. 5).

Barriers relating to the organizational context

Patients considered that a main obstacle to ACP implementation, from an organizational and institutional perspective, was the fact that it is a laborious process and that the document itself was difficult to complete (Sharp et al., 2013; Ke et al., 2015). The use of terminology that patients and their family members found difficult to understand also constituted a barrier (Ke et al., 2015). Patients and relatives also reported lack of time and continuity in the care process as impediments (Mignani et al., 2017). Moreover, two reviews with a methodological quality of 70% found that the main obstacle relating to the organisational context was patients' difficulties in performing the ACP (Sharp et al., 2013; Ke et al., 2015) (Fig.5).

(Please insert Figure 5)

Discussion

The umbrella review's synthesis of evidence collected qualitative data from scientific publications on the barriers to ACP perceived by professionals, patients and family members, in addition to providing data on their methodological quality. Fourteen systematic reviews of qualitative and quantitative studies (Lewis et al., 2015; Sharp et al., 2013; De Vleminck, et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans, Moll van Charante, & Willems, 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian, et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett, et al., 2014) were included; all focusing on the barriers perceived by professionals, patients and family members to the implementation of ACP. The methodological quality of these reviews was moderate to high.

Most of the reviews addressed the barriers relating to the implementation of ACP of patients at the end of life (Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014). The 14 studies finally obtained (Lewis et al., 2015; Sharp et al., 2013; De Vleminck, et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans, Moll van Charante, & Willems, 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian, et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett, et al., 2014), probably due to an increased rate of completion of the document by patients with chronic disease and a limited life expectancy (Glaudemans et al., 2015).

Regarding the perceived barriers relating to nursing and medical staff, professionals, patients and their families all agreed that lack of knowledge and skills for implementing ACP, as well as a lack of clarity regarding who should take the responsibility for the therapeutic relationship were barriers to implementation. Clearly, the existing ACP regulatory framework is still insufficient to ensure that the process unfolds correctly, and there is a need for specific training and qualification as well as leadership for implementing ACP. Professionals report concerns regarding these deficiencies (Lewis et al., 2016; De Vleminck et al., 2013; Ke et al., 2015; Flo et al., 2016; Jabbarian et al., 2017; Lun, Richardson, & May, 2015; Luckett et al., 2014). Improvements may be achieved by conducting ACP training programmes at health centres (Johnson e al., 2016; Shields et al., 2014; Luckett et al., 2014) or by providing clinical practice guidelines that would also define the stages and responsibilities related to ACP implementation, which are particularly necessary in cases where professionals have less experience in the field (Glaudemans et al., 2015).

Moreover, with regard to the social context, the need to take advance decisions regarding future treatments or interventions generates fear, and this fear emerges as a significant barrier to ACP management. Professionals express this fear when they approach their patients and find it difficult to judge the best moment to discuss ACP, due to the uncertainty of the prognosis and the patients' especially vulnerable state (Lewis et al., 2016; Flo et al., 2016; Johnson et al., 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Luckett et al., 2014). For their part, patients are also afraid to raise the question with their families, for fear of losing hope; they prefer to leave end-of-life conditions and circumstances to chance, to the will of their relatives, or to their God (Lewis et al., 2016; Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Glaudemans et al. 2015; Johnson et al. 2016; Jabbarian et al., 2017; Lund, Richardson, & May, 2015; Van De Steen et al., 2014)– ironically, perhaps, as ACP was initially designed as a mechanism to increase their feeling of empowerment. It might in fact be possible to distinguish between patients who suffer unpredictable exacerbation of their disease and are not offered ACP and other patients whose course is more predictable and who would benefit from ACP (Glaudemans et al., 2015). On the other hand, many patients and their family members prefer to talk to their physician, someone who knows them and with whom they already have a therapeutic relationship that allows them to address intimate issues such as illness, incapacity and death (Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Luckett et al., 2014).

At organizational level, the 14 reviews included in this study suggested that nursing and medical professionals' lack of time to talk with patients about ACP was an important barrier to its implementation (Sharp et al., 2013; De Vleminck et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014). The 14 studies finally obtained (Lewis et al., 2015; Sharp et al., 2013; De Vleminck, et al., 2013; Ke et al., 2015; Lovell, & Yates, 2014; Glaudemans, Moll van Charante, & Willems, 2015; Flo et al., 2016; Johnson et al., 2016; Mignani et al., 2017; Shields et al., 2014; Jabbarian, et al., 2017; Lund, Richardson, & May, 2015; Van Der Steen et al., 2014; Luckett, et al., 2014). Other barriers included the difficulties of professionals to access ACP computerized records in order to establish which patients had advanced directives and which did not (Lewis et al., 2016; Ke et al., 2015; Flo et al., 2016; Johnson et al., 2016; Shields et al., 2014; Lund, Richardson, & May, 2015) as well as the lack of continuity of care between patients' primary care and hospitals (Mignani et al., 2017). Another important point is the fact that, these documents are extremely prescriptive, leading professionals and patients in some cases to tick boxes rather than facilitating shared dialogue and discussion in which wishes and preferences relating to care are valued and protected (Johnson et al., 2016). Humanization models of assistance and person-centred care aim to nurture a conducive environment, providing enough time to fulfil the entire ACP process. Understanding the barriers to ACP can help to change the organizational culture, create new structures, and introduce new ways of enhancing the respect of the principle of autonomy for patients when deciding about their health.

Finally, the perception of a lack of autonomy among nurses with regard to ACP and the absence of a clearly identifiable professional in charge of managing the process have meant that nurses are often attributed this role. Indeed, the Palliative Nursing Summit issued recommendations to include ACP in all the standards of practice of all nursing specialities (Mazanec et al., 2018).

Limitations and strengths

The main limitation of the present study is that an Umbrella Review is based on the existing results of different reviews and, therefore, the quality of the studies is to a certain extent assumed a priori. To tackle this limitation, three authors independently determined the methodological quality of each review using PRYSMA and Joanna Briggs recommendations for the evaluation process of the scientific quality.

As for its strengths, this Umbrella Review provides a quick and comprehensive view of the research carried out so far on the barriers to ACP implementation at healthcare centres. It represents a novel qualitative synthesis of the evidence on the subject.

Conclusion

In conclusion, organizations need to implement cultural and structural changes to overcome barriers, focusing all the attention on the patient and, consequently, placing patients at the heart of decision-making where their preferences and values are taken into account by trained and qualified ACP professionals.

Anonymised conflict of interest statement

The Authors declares that there is no conflict of interest.

Ethical considerations and consent to participate

This umbrella review was conducted following standards of good scientific practice in every phase.

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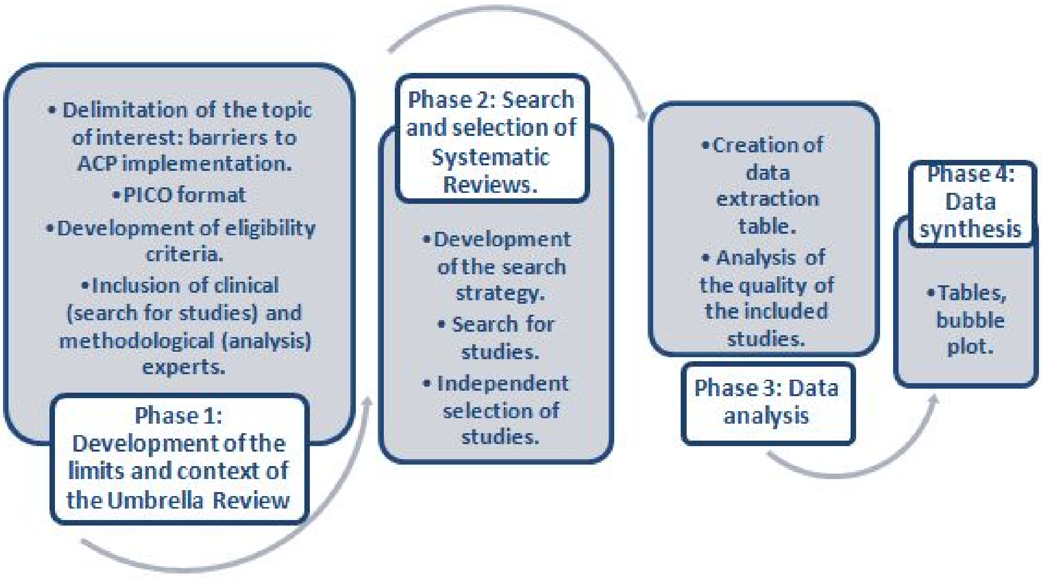

Fig. 1. Phases of the Umbrella Review. Adapted from Ballesteros et al. (2017)

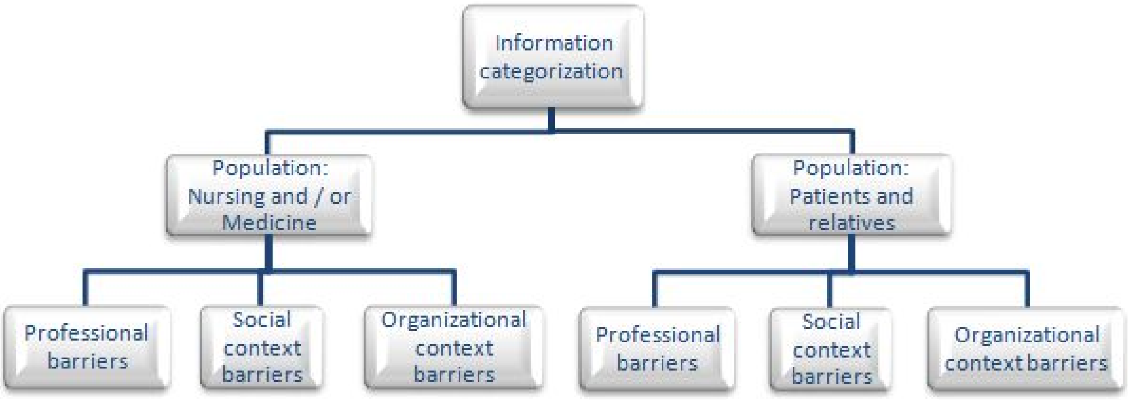

Fig.2. Information categorization process

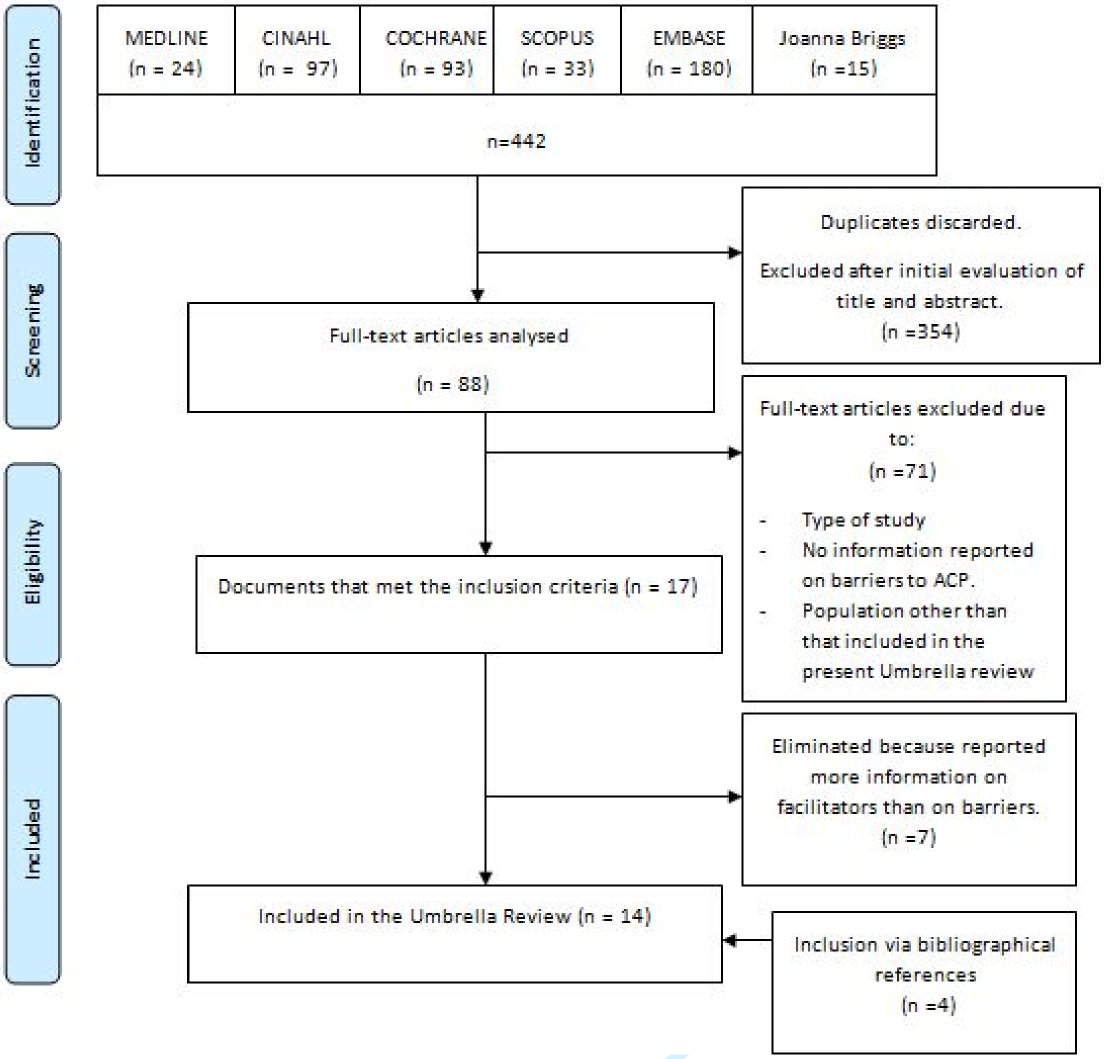

Fig.3. PRISMA flow diagram detailing identification and selection of studies were for inclusion.

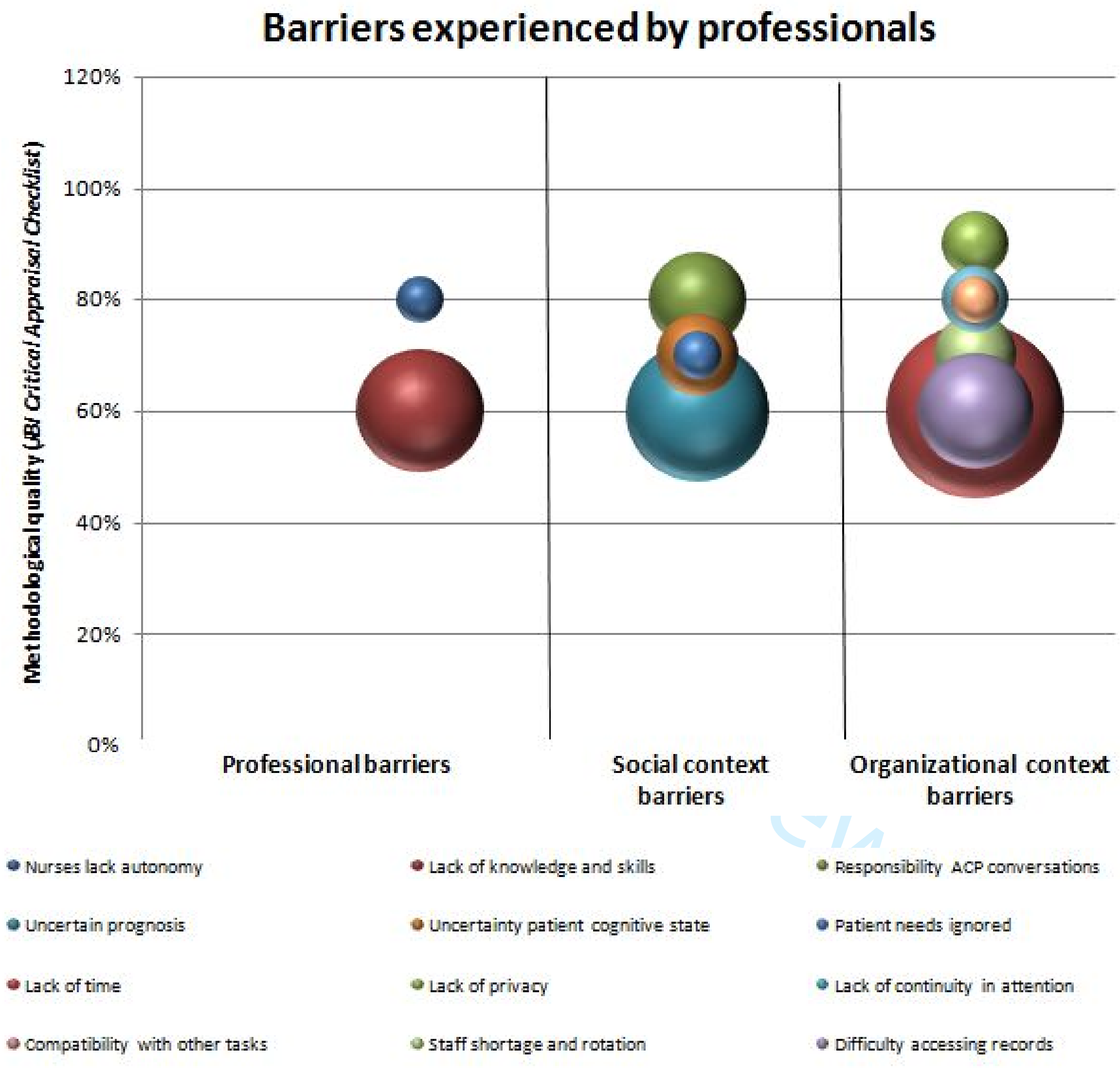

Fig. 4. Bubble Plot. Barriers experienced by professionals

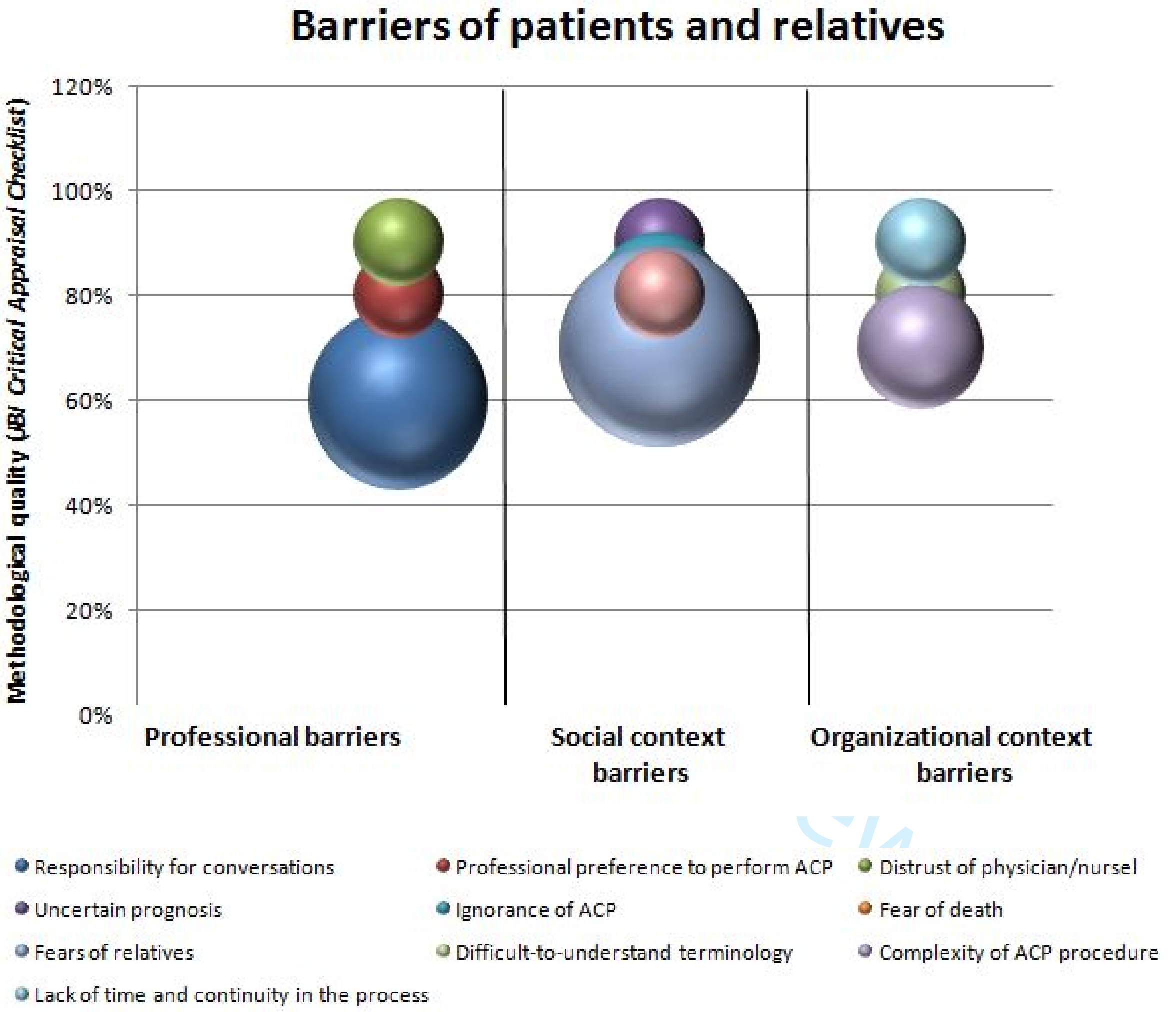

Fig. 5 . Bubble Plot. Barriers of patients and relatives

- ***Population:***nursing and/or medical professionals, patients and family members.
- ***Phenomenon of interest:***experiences and/or perceptions of ACP (translated into barriers) that hinder its implementation.
- ***Context:*** Primary Care, Urgent Care, Palliative Care, Acute/Chronic Hospitalization and/or residential centres.

Type of studies: metasyntheses and systematic reviews of qualitative and quantitative studies.

Table 1. Inclusion criteria in PICo format adapted for umbrella reviews according to JBI and type of studies.

	Results
MEDLINE	
#1. (("Advance Care Planning"[Mesh]) OR "Advance Directives"[Mesh]) OR "Living Wills"[Mesh]))	24
#2. barriers OR barrier* OR facilitators barriers OR communication barriers	
#3. health professional* OR health care professional* OR health care provider* OR medical staff* OR nurse* OR nursing staff* OR staff nurse* OR nursing practitioner* OR nurse practitioner*	
#4. patient OR elderly patient* OR critically ill patient* OR patient care* OR hospitalized patient* OR patient experience*	
#5. #1 AND #2 AND #3 AND #4	
Filters: Meta-Analysis, Review, Scientific Integrity Review, Systematic Reviews	
CINAHL	
#1. advance care planning OR advanced directives OR advance directives OR living will	97
#2. health professionals OR (health professionals or nurses) OR nursing OR nurse	
#3. barriers OR barriers to communication OR (barriers or obstacles or challenges) OR barriers to change OR issues	
#4. (meta-analysis or systematic review) OR review	
#5. #1 AND #2 AND #3 AND #4	
Joanna Briggs	
#1. Advance Care Planning or Advance Directives or Living Wills	15
#2. barriers or barrier* or facilitators barriers or communication barriers	
#3. #1 AND #2	

Table 2. Search strategy

	Results
SCOPUS	
#1. Advance Care Planning OR Advance Directives OR Living Wills #2. barriers OR barrier* OR facilitators barriers OR communication barriers #3. health professional* OR health care professional* OR health care provider* OR medical staff* OR nurse* OR nursing staff* OR staff nurse* OR nursing practitioner* OR nurse practitioner* #4. patient OR elderly patient* OR critically ill patient* OR patient care* OR hospitalized patient* OR patient experience* #5. #1 AND #2 AND #3 AND #4 Filter: Review	33
Cochrane library	
#1. Advance Health Care Planning OR advance directives Advance Directive OR Directive, Advance OR Directives, Advance OR Health Care Power of Attorney OR Advance Medical Planning OR Medical Planning OR Advance Planning OR Advance Medical #2. Care Planning OR Patient Planning OR Patient Care OR Nursing Care Plans OR Care Plan, Nursing OR Care Plans, Nursing OR Nursing Care Plan OR Plan, Nursing Care OR Plans, Nursing Care OR Goals of Care OR Care Goal OR Care Goals #3. #1 AND #2	93
EMBASE	
#1.'advance directives':ab,ti OR 'advance care planning':ab,ti OR 'advance care plan' OR 'advanced directive' OR 'advance health care plan':ab,ti #2.'barrier' OR 'barriers':ab,ti OR 'communication barriers':ab,ti #3.'health professional':ab,ti OR 'health care professional':ab,ti OR 'health care provider':ab,ti OR 'medical staff':ab,ti OR 'nurse':ab,ti OR 'nursing staff'/exp OR 'nursing staff' OR (('nursing'/exp OR nursing) AND n('staff'/exp OR staff)) OR 'staff nurse'/exp OR 'staff nurse' OR (('staff'/exp OR staff) AND ('nurse'/exp OR nurse)) OR 'nursing practitioner' OR (('nursing'/exp OR nursing) AND ('practitioner'/exp OR practitioner)) OR 'nurse practitioner'/exp OR 'nurse practitioner' OR (('nurse'/exp OR nurse) AND ('practitioner'/exp OR practitioner)) #4. 'patient':ab,ti OR 'elderly patient':ab,ti OR 'critically ill patient':ab,ti OR 'patient care':ab,ti OR 'hospitalized patient':ab,ti OR 'patient experience':ab,ti #5. 'family':ab,ti OR 'family support':ab,ti OR 'family centered care':ab,ti OR 'family caregiver':ab,ti OR 'family care':ab,ti #6. #2 AND #3 AND #4 AND #5 #7. #1 AND #6	180

Table 2. Search strategy (continuation)

STUDY	OBJECTIVE	DESIGN	COUNTRY	STUDIES INCLUDED	POPULATION	CONTEXT	PHENOMENON OF INTEREST/BARRIERS		
							SOCIAL CONTEXT	HEALTH PROFESSIONAL	ORGANIZATIONAL CONTEXT
Lewis et al. (2016)	Determine whether ACP encourages health professionals to participate in end-of-life conversations.	Systematic review	Sydney, Australia	N=24 Quantitative, qualitative and mixed methodology	Patients, families, doctors, nurses, community care staff, government legislators and judges.	End-of-life	✓	✓	
Sharp et al. (2013)	To investigate the attitudes of the population and health professionals in ACP conversations with older people who have no overriding diagnosis.	Systematic review	Cambridge, UK	N=26 Quantitative, qualitative and mixed methodology	Elderly people, health professionals.	End-of-life	✓	✓	✓
De Vleminck et al. (2013)	Identify the perceived factors that hinder or facilitate GPs' participation in ACP with their patients, in end-of-life care.	Systematic review	Brussels, Belgium	N=16 Quantitative and qualitative methodology	GP doctors	Primary, end-of-life care	✓	✓	✓
Ke et al. (2015)	Explore the experiences and perspectives of nurses regarding the implementation of ACP.	Systematic review	Taipei, Taiwan	N=18 Qualitative methodology	Nursing professionals	Hospital and community environment	✓	✓	✓

Table 3. Synthesis, characteristics of the reviews and key results

STUDY	OBJECTIVE	DESIGN	COUNTRY	STUDIES INCLUDED	POPULATION	CONTEXT	PHENOMENON OF INTEREST/BARRIERS		
							SOCIAL CONTEXT	HEALTH PROFESSIONAL	ORGANIZATIONAL CONTEXT
Lovell et al. (2014)	Identify the contextual factors that influence the adoption of ACP in palliative care.	Systematic review	Brisbane, Australia	N=27 Quantitative, qualitative and mixed methodology	Patients in palliative care (the elderly, cancer patients) and health professionals.	Palliative care	✓	✓	
Glaudemans et al. (2015)	Provide a general overview of the real ACP practice in Primary Care.	Structured review	Amsterdam, The Netherlands	N=10 Quantitative and qualitative methodology	Nurses and doctors	Primary Care	✓	✓	
Flo et al. (2016)	Emphasise the importance of research in ACP implementation (topics and guiding questions, scenarios, facilitators, implementers, and barriers).	Scoping review	Bergen, Norway	N=16 Quantitative and qualitative methodology	Nurses, doctors and patients	Residential centres	✓	✓	✓

Table 3. Synthesis, characteristics of the reviews and key results (followed)

STUDY	OBJECTIVE	DESIGN	COUNTRY	STUDIES INCLUDED	POPULATION	CONTEXT	PHENOMENON OF INTEREST/BARRIERS		
							SOCIAL CONTEXT	HEALTH PROFESSIONAL	ORGANIZATIONAL CONTEXT
Johnson et al. (2016)	Explore the experiences and perceptions of patients, caregivers and health professionals of ACP in cancer care.	Systematic review	Sydney, Australia	N=40 Quantitative, qualitative and mixed methodology	Patients, caregivers and health professionals.	Cancer care, end-of-life.	✓	✓	✓
Mignani et al.(2017)	Explore the perspectives of the elderly, who live in residential centres, and their families on initiating ACP conversations.	Systematic review	Bologna, Italy	N=9 Qualitative methodology	Persons >65 years and family members	Residential centres	✓	✓	✓
Shields et al. (2013)	To examine reasons ACP is difficult to implement in psychiatry worldwide, by reviewing existing barriers.	Systematic review	Amsterdam, The Netherlands	N=30 Quantitative, qualitative and mixed methodology	Patients and health professionals (psychiatrists, psychologists and nurses)	Psychiatry	✓	✓	✓

Table 3. Synthesis, characteristics of the reviews and key results (followed)

STUDY	OBJECTIVE	DESIGN	COUNTRY	STUDIES INCLUDED	POPULATION	CONTEXT	PHENOMENON OF INTEREST/BARRIERS		
							SOCIAL CONTEXT	HEALTH PROFESSIONAL	ORGANIZATIONAL CONTEXT
Jabbarian et al. (2017)	Review ACP practice in cases of chronic respiratory disease, Attitudes of patients and health professionals, as well as ACP barriers and facilitators.	Systematic review	Rotterdam, TheNetherlands	N=21 Quantitative and qualitative methodology	Patients and health professionals	Chronic respiratory disease	✓	✓	✓
Lund et al. (2015)	Investigate ACP implementation barriers and facilitators, focusing on ACP management and integration in clinical practice.	Systematic review	Glasgow, UK	N=13 Quantitative and qualitative methodology	Nursing professionals, patients and family members.	Health centres	✓	✓	✓
Van der Steen et al. (2014)	Identify the factors associated with the start of ACP in relation to end-of-life problems in dementia.	Systematic review	Amsterdam, TheNetherlands	N=33 Quantitative, qualitative and mixed methodology	Patients and health professionals.	End-of-life	✓	✓	✓

Table 3. Synthesis, characteristics of the reviews and key results (followed)

STUDY	OBJECTIVE	DESIGN	COUNTRY	STUDIES INCLUDED	POPULATION	CONTEXT	PHENOMENON OF INTEREST/BARRIERS		
							SOCIAL CONTEXT	HEALTH PROFESSIONAL	ORGANIZATIONAL CONTEXT
Luckett et al. (2014)	Identify developed interventions and their effectiveness; identify the measures used in the intervention; report the barriers/facilitators of the implementation, as well as the perceptions of those involved.	Systematic review	Sydney, Australia	N=55 Quantitative, qualitative and mixed methodology	Patients, family members and health professionals.	Kidney failure, end-of-life.	✓	✓	

Table 3. Synthesis, characteristics of the reviews and key results (followed)

	FACTORS RELATING TOHEALTH PROFESSIONALS	% (Nº ARTICLES)	FACTORS RELATING TO THESOCIAL CONTEXT	% (Nº ARTICLES)	FACTORS RELATING TO THEORGANISATIONAL CONTEXT	% (Nº ARTICLES)
EXPERIENCES AND/OR PERCEPTIONS OF NURSES/ PHYSICIANS	- Lack of nurse autonomy to conduct ACP (34)	7% (1)	- Responsibility to start conversations about ACP (professional or patient)(30,31,34,37)	29% (4)	- Lack of time to start discussing ACP (27-40)	100% (14)
	- Professionals' lack of knowledge and skills (27,29,30,33,37, 38,40)	50% (7)	- Feelings of fear of depriving patients of hope (27,33,34,37,38,40)	43% (6)	- Lack of privacy (31,34)	14% (2)
			- Prognosis uncertainty (27-30,32,34,37-39)	64% (9)	- Lack of organisational support (33, 35-37)	29% (4)
			- Uncertainty about patient's cognitive status (27,28,30)	21% (3)	- Lack of continuity in care (28,37)	14% (2)
			- Not knowing patients' needs (32)	7% (1)	- Terminologies difficult to understand and differing terms according to the country (30)	7% (1)
					- Lack of collaboration between Primary and Hospital Care (29)	7% (1)
					- Compatibility with other clinical and organisational tasks (32, 38)	14% (2)
					- Shortage of personnel and rotation (28,29,33)	21% (3)
					- Difficulty accessing computerised records (27,30,33,34,36,38)	43% (6)
					- Legal implications (31,33)	14% (2)
					- Distinctive nature of the system seeking to "cure at all costs" (37)	7% (1)

Table 4. Barriers to ACP implementation

	FACTORS RELATING TO HEALTH PROFESSIONALS	**% (Nº ARTICLES)**	**FACTORS RELATING TO THESOCIAL CONTEXT**	**% (Nº ARTICLES)**	**FACTORS RELATING TO THEORGANISATIONAL CONTEXT**	**% (Nº ARTICLES)**
EXPERIENCES AND/OR PERCEPTIONS OF PATIENTS, CAREGIVERS AND/ OR FAMILY MEMBERS	- Responsibility to start conversations about ACP (professional or patient) (33-35, 40) - Preference to conduct ACP with the "most familiar" professional (34) - Patients' distrust of the professional (35)	29%(4) 7% (1) 7% (1)	- Prognosis uncertainty for family members (35). - Patients' lack of knowledge of ACP (30,34) - Patients' fear of death (28-30,33,39) - Fear of family members to start ACP conversations (28,30,34,35,39) - Cultural factors in ethnic minorities (39)	7% (1) 14% (2) 36% (5) 36% (5) 7% (1)	- Difficult terminologies for patients (30) - Complex process to complete the ACP (28.30) - Patients and family members claim a lack of time and continuity in the ACP process (35).	7% (1) 14% (2) 7% (1)

Table 4. Barriers to ACP implementation (followed)

Autor(es)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	% respuestas positivas
Jabbarian et al. (2017)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	91%
Ke et al. (2015)	N	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	82%
De Vleminck et al. (2013)	N	Y	U	Y	Y	Y	Y	Y	N	Y	Y	73%
Lund et al. (2015)	N	Y	Y	Y	U	Y	U	Y	N	Y	Y	64%
Shields et al. (2013)	N	Y	N	Y	Y	Y	U	Y	U	Y	Y	64%
Lovell et al. (2014)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	91%
Sharp et al. (2013)	Y	Y	Y	Y	Y	N	N	Y	U	Y	Y	73%
Lewis et al. (2016)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	91%
Van der Steen et al. (2014)	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	82%
Glaudemans et al. (2015)	N	Y	Y	Y	Y	U	Y	Y	U	Y	Y	73%
Flo et al. (2016)	Y	Y	Y	Y	U	Y	Y	Y	U	Y	Y	82%
Luckett et al. (2014)	N	Y	N	Y	Y	Y	U	Y	N	Y	Y	64%
Johnson et al. (2016)	N	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	82%
Mignani et al.(2017)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	91%

Y - Yes, N - No, U –Unclear

Table 5. Results of the critical evaluation of the studies included following JBI-URARI.

LINKING EVIDENCE TO ACTION

- An Umbrella Review compile qualitative or quantitative evidence from multiple reviews and perform a synthesis of the results on a topic of interest.
- This review has examined the barriers presented by health professionals, patients and family members; so that future lines of research can develop preventive or decisive measures that encourage the implementation of ACP in health care.
- This report indicated that lack of specific abilities and lack of time were revealed as the main barriers to implementing ACP.

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title page: Barriers to Advance Care Planning implementation in healthcare: An umbrella review.
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Abstract page: Background, aim, design, data sources, results and conclusions
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Page 2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Page 4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	There is no protocol
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Page 5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Page 5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Page 6

PRISMA 2009 Checklist

Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Page 6-7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Page 7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Page 5-6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Page 7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Page 7-8
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	Page 7-8

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Page 7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Bubble in the diagram: Page 7-8
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Page 8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Page 7-8
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Page 7-8
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Page 7-15
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Page 7-15
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Page 7-15
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Page 7-15
DISCUSSION			

PRISMA 2009 Checklist

Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Page 16
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Page 19
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Page 20
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Page 20

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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