Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: A systematic review

Abstract

Introduction
Advance care planning is a means for patients to communicate their wishes, fears and desires for future health decisions should they lose the ability to consider or communicate these. Despite being supported by governments and healthcare leaders, uptake amongst the general population remains low. Nurses play a crucial role in promoting and engaging with these discussions given their close relationship with patients and families in a range of clinical settings.

Aim
The aim of our review was to describe the barriers that nurses and healthcare professionals believe prevent them from exploring advance care planning with their patients.

Method
We carried out a systematic review of peer-reviewed journal articles from the databases MEDLINE, Embase, CINAHL Plus, Web of Science and ProQuest Central), guided by the PRISMA checklist.

Results
Eleven articles were identified: all were self-reporting surveys using a mix of open and closed questions. They originated in the USA, Canada, Australia and
Ireland. The participants were primarily nurses, but some focussed on other healthcare professionals.

The two most important barriers to advance care planning are lack of education and insufficient time. The concept appears to be well supported and nurses and healthcare professionals report themselves to be comfortable and confident to take on the responsibility.

**Conclusion**

There is a need for greater education and training for nurses and healthcare professionals. In particular, there needs to be better understanding of professional and legal responsibilities. The need for sufficient time to be made available to allow these conversations, in often busy settings, will need institutional and financial support.

**Relevance to Clinical Practice**

Increased training and knowledge are likely to lead to more positive attitudes and greater confidence for nurses, and other healthcare professionals, which should help support and encourage patient engagement with advance care planning.

**Impact Statement**

What does this paper contribute to the wider global clinical community?

- Advance care planning is a priority for healthcare systems around the world, seeking to preserve a patient’s autonomy in times of incapacity and provide clinicians with insight into the wishes, preferences and values of patients.
- This review demonstrates that nurses and other healthcare professionals support the principles of advance care planning.
• However, a lack of time and training is preventing it from becoming a part of routine practice.

**Key Words**

Advance care planning [MeSH]

Advance directives [MeSH]

Surveys and questionnaires [MeSH]

Health personnel [MeSH]

Nurses [MeSH]
**Introduction**

Advance care planning is the practical application of a fundamental principle of law and medical ethics, that “a competent adult patient once properly informed has the unassailable legal right to refuse any or all medical treatment or care” (Re B (Adult: Refusal of Medical Treatment), 2002). The nature of critical illness is one that often results in a loss of capacity (Raymont et al., 2004) meaning patients are excluded from important decisions about their care unless their wishes have been discussed and/or documented in advance. The idea of an individual indicating in writing ahead of time the extent to which he/she would consent to treatment, a ‘living will’, was first proposed by the Euthanasia Society of America in 1967 (Sabatino, 2010). Subsequently, the idea of a ‘power of attorney’ for healthcare, allowing a nominated individual to make decisions in case of incapacity, was mooted and these became incorporated into law and were widely adopted in the United States (Sabatino, 2010). The shortcomings of so-called ‘living wills’, particularly the narrow range of situations and decisions to which one document could apply, and the potential of abuse inherent in powers of attorney meant that by the 1990s ‘advance directives’ were recognised as an inadequate tool, if used alone, to ensure good decision making whilst caring for a terminally ill patient (Curd, 1999). A more global term of advance care planning was adopted with an emphasis on the broader process of communication as opposed to the completion of any particular form (Teno, Nelson, & Lynn, 1994).

There is currently no standardised data on advance care planning discussions or advance directive completion rates making it difficult to understand their prevalence in the general population. Data that are available indicate that uptake can vary significantly by study with a systematic review of US studies finding the reported prevalence of advance directive completion ranging from 0 to 93.8% (Yadav et al., 2017). This review concluded that approximately 1 in 3 US adults have completed some form of advance directive whilst data from
Australia and Europe suggests completion rates of ~14% (White et al., 2014) and ~4% (De Vleminck et al., 2015; Royal College of Physicians, 2016) respectively. These relatively low levels are despite many countries having public health campaigns and charities designed to promote advance care planning (Austin Health, 2018; Dying Matters, 2018; The Conversation Project, 2018). This could be explained by a lack of appetite on behalf of the public, however surveys suggests high levels of support for the idea of discussing death and planning for end of life (NatCen Social Research, 2013). Another possibility, and one which this review will explore, is of difficulties which healthcare professionals experience when having, or attempting, advance care planning discussions with patients. Advance care planning happens in a range of settings including nursing and care homes, hospices, hospitals and within primary care. Nursing staff are frequently present and will often have the greatest ‘face-to-face’ contact with patients, and families, placing them in key positions to facilitate advance care planning (Newton, Clark, & Ahlquist, 2009). Nursing regulatory bodies consider supporting patient self-determination and decision making a core proficiency of practice (American Nurses Association, 2015; Nursing & Midwifery Council (NMC), 2018) and there is consensus that nurses should be playing a pivotal role in helping patients understand, explore and communicate their preferences regarding future medical treatments and end of life care (Briggs & Colvin, 2002).

Cabana et al., (1999) utilised a framework of knowledge, attitudes and behaviour to map the barriers preventing physicians from adhering to clinical guidelines and we believe that this framework would also be suitable for mapping the barriers towards ACP. Knowledge, attitudes and practice (or behaviour) studies (KAPs) are representative surveys of a specific population aiming to discover what is known, believed and done in relation to a particular topic (WHO, 2008). KAPs have traditionally been carried out by aid organisations in developing countries but their advantages of speed, low cost
and generation of quantitative data, which can be inferred on to a larger population, has meant that they have been adopted on mass and are a frequently used tool to assess both public and professional populations (Hausmann-Muela, Ribera, & Nyamong, 2003; Launiala, 2009). They can reveal widespread misunderstandings, misconceptions and obstacles to implementation or adherence of a policy or programme (Cabana et al., 1999).

**Aims**

The aim of this systematic review was to identify the barriers to advance care planning discussions with patients as reported by nurses and other healthcare professionals and identified in KAPs.

Several systematic reviews have focussed on either healthcare professionals' knowledge (Kermel-Schiffman & Werner, 2017), attitudes (Ke, Huang, O'Connor, & Lee, 2015) or practices (Jabbarian et al., 2018) towards advance care planning, mainly exploring these categories independently. The advantage of focussing on KAPs is that all domains of knowledge, attitude and practices are assessed and these can be analysed in relation to each other, exploring potential interactions. Additionally, our decision to focus on KAPs was influenced by our desire to make a methodological contribution to the field by assessing the content and quality of published KAPs and discussing their suitability for expanding our understanding of advance care planning. To our knowledge, this is the first review to explore the use of KAPs in advance care planning.

**Methods**

**Design**

This was a systematic review of the literature. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement was used to guide the review (Moher et al., 2015) (See Supplementary File 1). A review protocol was registered in PROSPERO: registration number CRD42018055253.
Research questions

The review was guided by the following questions:

- Have KAPs been carried out on healthcare professionals in regard to advance care planning?
- What were the barriers to advance care planning in terms of knowledge, attitudes and practice for healthcare professionals and are there interactions between these?
- What is the methodology and quality of KAPs assessing healthcare professionals' in regard to advance care planning?

Search Strategy

The authors, one social scientist (CVP) and four clinicians (DHB, DW, MGM and RMT), conducted a review of peer-reviewed journal articles using multiple databases between February and April 2018: MEDLINE, Embase, CINAHL Plus, Web of Science and Proquest Central. Additionally, the grey literature was searched using the databases OpenGrey and Trip. The search used a combination of keywords and subject headings for the concepts of KAPs, healthcare professionals and advance care planning / end of life decision making (example search strategy in supporting information). Results were combined into Mendeley, and duplicates were removed. The reference lists of included articles were screened to identify additional relevant publications.

Study selection

Two authors (CVP and DB) screened the articles in three phases (title and article type (DB), abstract (CVP and DB) and full text (CVP and DB)) based on the following criteria:

- They fulfilled the criteria of a KAPs,
- They focussed on healthcare professionals, and,
- They investigated advance care planning / end of life discussions.
When there was disagreement the reviewers discussed their responses until agreement was reached.

The authors adopted USAID’s definition of a Knowledge, Attitudes and Practice study as “a quantitative method (predefined questions formatted in standardized questionnaires) that provides access to quantitative and qualitative information” (USAID, 2011). Studies which did not meet this definition or did not look at all three domains of knowledge, attitudes and practice were excluded.

The authors adopted a definition of healthcare professionals as “individuals who maintain health in humans through the application of the principles of evidence-based medicine and caring”. This has been adapted from a definition previously used by the WHO (WHO, 2013). The aim of this review was to include all those who may have advance care planning conversations with patients and so the definition of healthcare professionals was as broad as possible.

This review looked at advance care planning discussions which necessitates that these are conversations about future care. Advance care planning is related to, but distinct from, shared decision making, which aims to combine a healthcare professionals' expertise with a patient’s values and goals in order to make a treatment decision (NHS England, 2018). Advance care planning takes place in the context of an anticipated deterioration in an individual’s condition, where there is a concern that they will be unable to offer views or make decisions at a later time (NHS Improving Quality, 2014). In different countries, differing terminology is used to describe advance care planning. A broad definition of advance care planning would be as “a process of discussion between an individual, their care providers, and often those close to them, about future care” (Royal College of Physicians et al., 2009). For the purposes of this review advance care planning is used to describe the process of discussion,
which may or may not result in a written document, and the term advance directive shall refer to any documentation of values, goals, concerns and/or preferences. Every effort was made to include all studies which looked at this concept regardless of terminology.

We did not exclude articles based on publication date but had to limit the selection to articles published in English.

Data extraction
Study data were collected and managed using a data extraction form developed in Microsoft Excel. The form was developed after the initial screening of full-text articles. The principal categories used in this form were knowledge, attitudes and practice. Nine (Beck et al., 2017; Downe-Wamboldt, Butler, & Coughlan, 1998; Jezewski & Feng, 2007; Jezewski, Meeker, & Schrader, 2003; Lipson, Hausman, Higgins, & Burant, 2004; Putman-Casdorph, Drenning, Richards, & Messenger, 2009; Scherer, Jezewski, Graves, Wu, & Bu, 2006; Sellars et al., 2015; Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010) of the eleven studies divided either the questionnaire or their results sections into these categories which guided data extraction. For those which did not, the authors placed answers in the category they felt was most appropriate.

Data synthesis
Data were exported from the spreadsheet and the main article characteristics collated and presented. As multiple different questionnaires were used with a wide degree of variation in terms of questions and topics covered it was not possible to undertake meta-analysis or other statistical techniques. Instead the authors used a qualitative approach. Articles were analysed using thematic analysis (Braun & Clarke, 2006) to allow for the identification of patterns across the data set. A broadly descriptive type of thematic analysis was employed when developing the themes. DB read the articles numerous times to ensure immersion making initial notes of potentially interesting aspects. Following from
this, the entire data set was coded by DB. A review of the coding of the
dataset, including the codes used, was performed by CVP. The dataset was
then reread and recoded with codes added, modified or removed as required
to ensure the dataset was coded consistently. Potential themes were then
identified with relevant data collected under each theme. The quality of studies
was assessed and reported separately.

Quality assessment
Currently there is no commonly used reporting guideline for survey research,
although multiple checklists have been described and/or used in the literature
(Bennett et al., 2011). Bennett et al. (2011) reviewed the availability of guidance
for reporting survey research from major journals as well as reviewing published
studies on the quality of survey reporting. From this, 33 items were identified as
critical to reporting survey research. Each of these was used to assess the
articles included in the review. Articles which reported >75% of these criteria
were rated good; 50-75% moderate and <50% poor.

Results
Identification of studies
The initial search yielded 2,217 articles (206 from CINAHL, 482 from EMBASE, 634
from ProQuest, 238 from PubMed, 640 from Web of Science, 1 from OpenGrey
and 16 from Trip). Once duplicates were removed, there were a total of 1,388
articles. These were screened based on title of article, resulting in 66 (Figure 1).
Screening based on abstracts left 24 articles for full text review. Screening of the
full texts led to 11 articles meeting the inclusion criteria. A review of the
references of the articles did not find any further articles which met the inclusion
criteria.

One study (Snyder et al., 2013) did not ask respondents questions about their
knowledge of advance care planning. This study had a broader remit exploring
the knowledge, attitudes and experience of physicians in regard to palliative
care and hospice care in addition to advance care planning. The authors discussed the inclusion of this study and felt that although the lack of knowledge questions about advance care planning was a limitation the study still met the inclusion criteria of being a KAPs and investigating advance care planning and therefore should be included.

**Study characteristics**

The characteristics and results of the 11 studies included in the review are presented in Table 1. Eight of the articles originated in the USA, one was from Canada, one from Australia and one from Ireland. Despite searching the grey literature, no articles were found which met the inclusion criteria. The participants included nurses (eight), primary care physicians (one), home care package managers1 (one) and nursing home managers (one).

All studies were self-administered questionnaires either on paper (nine) or online (two). The majority (ten) used a mixture of closed and open-ended questions, however one study used purely closed questions (Sellars et al., 2015). Eight studies described newly developed or modified instruments (Beck et al., 2017; Downe-Wamboldt et al., 1998; Duke et al., 2007; Jezewski et al., 2005; Lipson et al., 2004; Sellars et al., 2015; Snyder et al., 2013; Zhou et al., 2010) whilst the other three used one of these eight instruments. A description of how survey instruments were developed and how validity and reliability were established is provided in

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1 Home care package services are funded by the Australian Government to facilitate the provision of personal support and clinical care services to elderly clients (aged >65 years) so that they can remain at home for as long as possible. Case managers, in collaboration with the client and family, coordinate and reviews the care services the clients receive.
Quality Assessment

The 33 items identified as critical to reporting survey research by Bennett et.al were assessed for the 11 included studies by DB and the results are presented in Table 3. One study was rated as of good quality (Lipson et al., 2004) and the rest of moderate quality. Three studies provided the full questionnaire whilst seven provided core questions and only one failed to provide either. Five newly developed, or modified, instruments reported both the validity and reliability, one reported validity only, one reported reliability only and one reported neither. Three studies used a previous instrument and referenced the original paper reporting both validity and reliability. All studies reported the response rate and ten defined how this was calculated. Three studies discussed the representativeness of the sample, and five identified how missing data were handled.

Knowledge healthcare professionals have about advance care planning

Nurses rated themselves and scored highly on the more general questions about advance care planning/advance directives including definitions and purpose (Jezewski & Feng, 2007; Jezewski et al., 2005; Lipson et al., 2004; Putman-Casdorph et al., 2009; Scherer et al., 2006; Zhou et al., 2010) whilst nursing home managers and home care package case managers scored poorly and lacked confidence in their levels of knowledge (Beck et al., 2017; Sellars et al., 2015). Questions about specific legislation whether that be national or state were typically answered poorly by all (Beck et al., 2017; Downe-Wamboldt et al., 1998; Jezewski & Feng, 2007; Jezewski et al., 2005; Putman-Casdorph et al., 2009; Scherer et al., 2006; Zhou et al., 2010).
Attitudes of healthcare professionals to advance care planning

Overall healthcare professionals had a positive attitude towards advance care planning/advance directives (Downe-Wamboldt et al., 1998; Duke et al., 2007; Lipson et al., 2004; Sellars et al., 2015; Zhou et al., 2010) believing they were helpful (Downe-Wamboldt et al., 1998; Duke et al., 2007), valuable and worthwhile (Sellars et al., 2015) although one study involving acute care and outpatient oncology nurses reported moderately negative attitudes (Putman-Casdorph et al., 2009). Three studies (Jezewski & Feng, 2007; Jezewski et al., 2005; Lipson et al., 2004) found that nurses agreed that patients should have the right to refuse treatment even if to do so would lead to death and that patients should always be informed of their condition and treatment alternatives. A participant in one study (Downe-Wamboldt et al., 1998) expressed difficulty when dealing with an advance directive when “you don’t agree with the decision” but three other studies (Jezewski & Feng, 2007; Jezewski et al., 2005; Scherer et al., 2006) found a high level of agreement for the principle that nurses should uphold patients decisions even if they disagree. Two studies (Downe-Wamboldt et al., 1998; Putman-Casdorph et al., 2009) found agreement that nurses consider advance care planning discussions as part of their role, whilst the studies involving home care package case managers (Sellars et al., 2015) and nursing home managers (Beck et al., 2017) found around half agreeing that it was part of their responsibilities. Interestingly, the one study which focussed on physicians found that they felt that it was patients and/or families who erect barriers to successful advance care planning conversations. The study involving nursing home managers (Beck et al., 2017) found that they felt that their patients do not want to know about future options and that around a third felt advance care planning discussions may negatively impact a patient’s sense of hope.
Current practices of healthcare professionals in advance care planning

Studies demonstrated varying levels of experience of advance care planning/advance directives with one finding 72% of nurses claiming no experience with advance directives at all (Downe-Wamboldt et al., 1998) whilst others found between 56-98% had cared for patients with an advance directive (Duke et al., 2007; Jezewski & Feng, 2007; Scherer et al., 2006). Two studies found over 75% of nurses had initiated an advance care planning conversation with a patient (Jezewski & Feng, 2007; Scherer et al., 2006). The study involving home care package case managers found 70% had initiated an advance care planning conversation in the last 12 months, although most of these did not progress to the documentation of wishes (Sellars et al., 2015). Physicians reported only having advance care planning discussions with 43% of patients who were chronically ill and 63% of patients who were terminally ill (Snyder et al., 2013).

In three studies, participants expressed concern that patients’ wishes would not be respected despite having an advance directive (Downe-Wamboldt et al., 1998; Duke et al., 2007; Snyder et al., 2013). In another three studies (Jezewski & Feng, 2007; Jezewski et al., 2005; Scherer et al., 2006), 17-48% of nurses reported having provided treatment prohibited by an advance directive themselves, whilst 42-63% had witnessed another healthcare professionals doing so.

Seven studies highlighted insufficient time as a major barrier to having advance care planning discussions with patients (Beck et al., 2017; Jezewski & Feng, 2007; Jezewski et al., 2005; Scherer et al., 2006; Sellars et al., 2015; Snyder et al., 2013; Zhou et al., 2010). A lack of knowledge and training were also identified by nursing home managers and home care package case managers as a reason for these conversations not taking place (Beck et al., 2017; Sellars et al., 2015). Staff discomfort and the difficult nature of talking about death was mentioned in two studies (Beck et al., 2017; Zhou et al., 2010) and a lack of knowledge or
desire on the part of patients and families was described in four (Jezewski et al., 2005; Scherer et al., 2006; Sellars et al., 2015; Zhou et al., 2010).

**Interactions of knowledge, attitudes and practice**

Nine studies (Beck et al., 2017; Duke et al., 2007; Jezewski & Feng, 2007; Jezewski et al., 2003; Lipson et al., 2004; Putman-Casdorph et al., 2009; Scherer et al., 2006; Snyder et al., 2013; Zhou et al., 2010) reported on the interactions between knowledge, attitudes and practice. Six studies showed a relationship between having greater knowledge and either having a more positive attitude (Beck et al., 2017; Jezewski & Feng, 2007; Lipson et al., 2004), greater self-reported practice of advance care planning (Lipson et al., 2004; Zhou et al., 2010), or higher levels of comfort when having such discussions (Duke et al., 2007; Lipson et al., 2004; Scherer et al., 2006). Two studies reported that greater experience of advance care planning discussions resulted in greater confidence (Jezewski et al., 2005; Putman-Casdorph et al., 2009), more positive attitudes (Jezewski et al., 2005) and a greater perception of these discussions as being part of a nursing role (Putman-Casdorph et al., 2009). One study showed no correlation between physicians reported comfort levels with advance care planning and their reported number of referrals to hospice or palliative care (Snyder et al., 2013).

**Discussion**

A major goal of governments and policy makers across the world is to work towards a ‘shared decision making model’ for healthcare as evidenced by legislation (111th Congress, 2010) and guidelines (National Institute for Health and Care Excellence (NICE), 2012). For those patients who lack capacity to make a medical decision, having previously engaged in advance care planning allows these decisions to be taken with an understanding of their wishes, values and preferences. Given that uptake of advance care planning remains low, discovering obstacles which may be preventing implementation of
advance care planning by healthcare professionals is critical if patients are to influence their treatment decisions when unwell and lacking capacity.

Many studies identified additional education and training as necessary for healthcare professionals in order to undertake advance care planning (Beck et al., 2017; Downe-Wamboldt et al., 1998; Duke et al., 2007; Jezewski & Feng, 2007; Jezewski et al., 2005; Lipson et al., 2004; Putman-Casdorph et al., 2009; Snyder et al., 2013). Nurses tended to know about the generalities of advance care planning but lacked an in-depth knowledge of the law. This is understandable, however, at times the lack of knowledge was so great that it could undermine the process of advance care planning. For instance, in one study only 7% of respondents were aware of the competency requirements for an advance directive and only 30% the witness requirements (Duke et al., 2007). Whilst in-depth knowledge of legal nuance cannot be expected, a basic level of understanding, including how to help a patient write a valid advance directive, is necessary. Nursing home managers and home care package case managers were found to be less knowledgeable than nursing staff. This is concerning, as in some contexts they may be in a good position to start such advance care planning discussions given that they have prolonged contact with patients, developing relationships with them and their families. This should make patients more comfortable when having these conversations.

Whilst not universal, it was found that healthcare professionals were broadly supportive of advance care planning and felt it was valuable for their patients. This meant that if appropriate time and training were available, they would be amenable to assisting patients with advance care planning. Even though there were some exceptions, negative attitudes of healthcare professionals do not appear to be a significant barrier to advance care planning discussions. The finding must be caveated with the knowledge that a degree of ‘courtesy bias’, where respondents provide the answers which they feel they ‘should give’ (Warwick, 1983, p. 236), may be present given the high profile support for
advance care planning amongst healthcare leaders. The surveys were anonymous in an attempt to mitigate this risk, however some respondents may still feel pressured to give what they perceive as the ‘correct’ answer. Additionally, none of the studies asked respondents to rank how important they felt advance care planning was in relation to other tasks and roles. It is possible that healthcare professionals may believe that advance care planning is positive and useful, but also think that it is of a much lower priority, or urgency, than other duties.

Following from this, the most common barrier identified by healthcare professionals was a lack of time to have these discussions. Advance care planning is now ‘billable’ in the USA with the ‘Current Procedural Terminology’ providing two codes; advance care planning, first 30 minutes, and advance care planning, each additional 30 minutes (American Medical Association, 2018). This suggests that at minimum advance care planning should take half an hour and may often last longer. In the context of a busy inpatient or clinic setting it may not be possible to dedicate this amount of time to one patient. The fact that the length of these discussions is unpredictable makes it additionally difficult for them to be scheduled within the working day. It may be that the fee-for-service model is better at promoting these discussions than a bundled payment or single provider model where communication may be seen as of lower priority compared to service delivery. Alternatively, a fee-for-service approach may turn the advance care planning discussion into a tick box exercise which focusses on provider as opposed to patient priorities.

Some healthcare professionals did admit to discomfort and difficulty talking about end of life issues and some reported negative experiences either having advance care planning conversations or following a patient’s advance directive. The majority of healthcare professionals, however, did feel comfortable and confident to engage in advance care planning and feelings of personal uneasiness was not seen as a major barrier. Conversely, the
expectation of advance care planning causing discomfort to either the patient or their relatives, was more commonly cited as a block on having these discussions. Whether this is accurate or whether healthcare professionals use this fear of causing distress as an excuse for avoiding advance care planning is not possible to ascertain from survey research alone. Additional research will need to be undertaken to explore the perceptions of patients in relation to having advance care planning discussions and their experiences of engaging in these conversations.

The most concerning finding of this review was that of healthcare professionals reporting that either themselves, or another, had acted against a patient’s advance directive. Healthcare professionals must respect the wishes of patients as expressed through advance directives for the process of advance care planning to have any credibility, not to mention that ignoring or subverting an advance directive is both bad professional practice and, in some cases, illegal. In 2017, a UK hospital trust was successfully sued for the artificial prolongation of a patient’s life against her expressed wishes as set out in an advance directive (Paduano, 2017).

There is a requirement for greater education and training of nurses, and others, to help them understand both advance directives and the advance care planning process. In particular, it is important for nursing staff to be aware of their legal and professional obligations in order to protect patients, but also to ensure they do not face punishment themselves. The fact that most studies found a positive attitude towards advance care planning would suggest that this education and training would be met with enthusiasm as opposed to resistance. As one of the barriers to advance care planning is effective communication, healthcare professionals in a position where these are required should be required to undertake advanced communication training. Training alone, however, will not be sufficient. There is a need for institutional and financial support if advance care planning is to become routine practice. In
particular, nurses need to be provided with adequate time, both to attend training and to have these conversations with patients in practice.

One of our goals was to evaluate the methodology and quality of KAPs in order to assess their usefulness outlining barriers to advance care planning. The major barriers we identified were time constraints (a practical barrier) and insufficient training and education (a knowledge barrier). It is likely that studies which only look at one domain, e.g. knowledge, will miss important factors which may be preventing nurses, and other healthcare professionals, from undertaking advance care planning discussions with patients. We also postulated that a major benefit would be the ability to assess the interactions between the knowledge, attitudes and practice of respondents. Nine of the eleven studies assessed these interactions finding that increasing knowledge and experience was associated with greater confidence and more positive attitudes. This is encouraging as it suggests there may be a virtuous circle whereby increased education and exposure to advance care planning promotes increasingly positive attitudes and a desire to incorporate it into practice. We believe that these advantages comprehensiveness and the assessment of interactions make KAPs a useful tool when exploring healthcare professional barriers to undertaking a behaviour or task. A potential disadvantage of KAPs is that they tend to eschew open-ended questions for the ease of data collection and so may not reveal new information or deepen understanding (Gumuchio, 2011). A potential strategy to reduce this risk would be to incorporate a KAPs into a mixed methods study which includes a qualitative component to allow for new ideas and concepts to be introduced by respondents.

This review should be interpreted with its limitations in mind. We tried to use the broadest possible search terms, however we may have missed articles that did not use these. Although all studies were KAPs and therefore focussed on knowledge, attitudes and practice there was a wide degree of variability of questions asked and topics covered. That studies from across the world were
included is both a strength and weakness of this review. It provides as broad an outlook as possible, but the different legal and cultural considerations in different countries make it difficult to draw overarching conclusions. Survey research has intrinsic limitations such as sampling bias, meaning results may not be generalisable to those who, for whatever reason, choose not to complete a questionnaire. A second caveat which applies to all survey research is that the practice, or behaviour, described is by necessity reported practice and therefore there is always a concern about informant accuracy (Lane, 1997). As mentioned previously, there is also a lack of validated reporting guidelines with which to assess quality. We have tried to address this by using a well evidenced tool to report indicators of quality but it is not clear how many ‘positive’ indicators would qualify a survey as of poor, moderate or good quality and the cut offs that we chose are arbitrary.

**Conclusion**

This review has highlighted the barriers healthcare professionals have which prevent the widespread implementation of advance care planning as desired by governments and healthcare leaders. The two most important are lack of education and insufficient time. There appears to be support for advance care planning from healthcare professionals and they report themselves as comfortable and confident to take on this responsibility. To allow them to do so, will require a significant investment in training and a reorganisation of current practice to allow space for advance care planning within the working day. Further research should include qualitative interview-based research to explore themes which may not have come up in the self-reported surveys and observational research to assess whether current practice reflects healthcare professionals self-reporting. Research looking at patients’ views of barriers to advance care planning discussions would also be interesting given that, in some cases, healthcare professionals will not engage in advance care planning
because they feel patients will refuse to have these conversations or will find these upsetting.

**Relevance to Clinical Practice**

In order for advance care planning to become a routine part of clinical practice increased focus on nurses, and other healthcare professionals, training and education is required. Increased knowledge is likely to lead to more positive attitude and greater confidence to undertake these discussions with patients. Additionally, institutional and financial support is imperative to ensure that nurses, and others, are provided with the time and opportunity to have occasionally long, and often unpredictable, conversations with patients.

**Author Contributions**

Conception and design of review – all authors

Search strategy, study selection and data extraction – DB & CVP

First draft of manuscript – DB

Critical revision of manuscript – all authors

All authors read and approved the final manuscript.
References


Launiala, A. (2009). How much can a KAP survey tell us about people’s knowledge, attitudes and practices? Some observations from medical anthropology research on malaria in pregnancy in Malawi. Anthropology


Royal College of Physicians. (2016). End of Life Care Audit - Dying in Hospital.


Sellars, M., Detering, K. M., Silvester, W., M, S., M, D. K., W, S., ... Silvester, W.


attitude and practice surveys. WHO/HTM/STB/2008.46

https://doi.org/10.1017/CBO9781107415324.004

https://doi.org/10.1377/hlthaff.2017.0175

https://doi.org/10.1188/10.ONF.E400-E410
### Tables

Table 1 Description, including results and limitations, of articles included in the review

<table>
<thead>
<tr>
<th>Authors</th>
<th>Country</th>
<th>Population</th>
<th>Knowledge</th>
<th>Attitudes</th>
<th>Practice</th>
<th>Limitations</th>
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<tr>
<td>Downe-Wamboldt</td>
<td>Canada</td>
<td>157/974 nurses</td>
<td>Nurses rated themselves as a mean of 7.4 on a 1-10 Likert scale (1 = very aware; 10 = not at all aware) of advance care planning/advance directives.</td>
<td>Nurses had a mean score of 2.7 on a Likert scale (1 = very helpful; 10 = not at all helpful) when asked about advance directives.</td>
<td>113/157 (72%) nurses stated they had no experience dealing with advance directives.</td>
<td>Poor response rate.</td>
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<td>133/157 (85%) knew the meaning of power of attorney for healthcare.</td>
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<td>Respondents were more highly educated than the typical registered nurse in Nova Scotia.</td>
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<td>Nurses had a mean score of 3 on a Likert scale (1 = very helpful; 10 = not at all helpful) when asked about the use of a surrogate.</td>
<td>120/157 (76%) nurses stated that they had no experience dealing with surrogates.</td>
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<td>128/157 (82%) believed incorrectly that an advance directive should be followed in a situation in which a surrogate for an incompetent person disagreed with the living will.</td>
<td>One response reflected a negative experience with advance directives: &quot;It is not easy, especially if you don't agree with the decision.&quot;</td>
<td>The 37/157 nurses who reported experience with living wills indicated that the majority of their patients were &gt;65 years old.</td>
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<td>Nurses had a mean score of 9.2 on a Likert scale (1 = agree strongly; 10 = disagree strongly) when asked whether advance directives restricted their nursing practice.</td>
<td>Nurses identified their role in relation to living wills as advocate (n=28), combination of roles (n=11), facilitator (n=5) and educator (n=2).</td>
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</tbody>
</table>
Nurses had a mean score of 9.1 on a Likert scale (1=agree strongly; 10=disagree strongly) when asked whether use of a surrogate restricted their nursing practice.

Nurses clearly identified lack of knowledge, legal concerns, lack of agency support, and ethical concerns as perceived barriers to the use of living wills in their practice.

Nurses had a mean score of 3.3 on a Likert scale (1 = totally agree; 10 = totally disagree) with the statement that nurses should promote the use of advance directives and surrogates with all of their patients.

Benefits (n = 7) were described for family, patients, and nurses: "I found a living will very beneficial to the care of my patients"; "Easier to deal with the family, patient more at ease"; "being aware of patient's and family's wishes makes nursing that person much easier."

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Sample Size</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Lipson (2004) (Lipson et al., 2004)</td>
<td>USA</td>
<td>719/1600 nurses</td>
<td>Nurses scored well (95-99% correct) on questions referring to definitions of advance directives. Nurses recorded moderately positive attitudes towards advance directives (M = 3.45; SD = 1.12; range of 1 to 5 with 5 = 7.3% rated themselves as extremely confident in their skill level in discussing advance directives with patients. 14% reported that they were not confident at all. Self-reporting means that accuracy of information is a concern.</td>
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</tbody>
</table>
strongly agree and 1 = strongly disagree).

57% nurses incorrectly answered a question referring to documentation of signing procedures. Nurses disagreed that advance directives represent an unwarranted extension of the law into medicine (M = 1.85; SD = .81).

15% had exposure to advance directive information in nursing school. Higher age, greater years nursing experience and higher level of education correlated negatively with reported levels of advance directive discussions with patients.

Nurses disagreed that prolonging life is more important than honouring a patient's request to forgo life-sustaining treatment (M = 1.41; SD = .63).

15% had exposure to advance directive information in nursing school. Higher age, greater years nursing experience and higher level of education correlated negatively with reported levels of advance directive discussions with patients.

Nurses disagreed that advance directives will lead to acceptance of euthanasia and that denial of treatment for terminally ill patients because of cost is acceptable. 17% answered that they had provided treatment to patients whose advance directive indicated otherwise, and 42% had observed others providing treatment to patients whose advance directive indicated otherwise.

Respondents disagreed with statements stating that advance directives will lead to acceptance of euthanasia and that denial of treatment for terminally ill patients because of cost is acceptable. 17% answered that they had provided treatment to patients whose advance directive indicated otherwise, and 42% had observed others providing treatment to patients whose advance directive indicated otherwise.

Low response rate (23%) response rate meaning that sampling bias may be present.

High level of agreement that nurses should uphold the patient's wishes even if they conflict with the nurse's own view. 52% agreed nurses often have insufficient time to discuss advance directives with patients. Only 12% believed that nurses spend enough time discussing advance directives with patients.

Results may not be generalisable to those outwith the 4 states surveyed.

High level of agreement that patients with decision-making capacity who are not terminally ill should have a right to refuse life support even if they conflict with the nurse's own view. Two-thirds or more of the nurses were confident (scores of 4 and 5 on the 5-point Likert scale) when discussing advance directives with patients and families and answering their questions.

Low internal consistency for subscales about attitudes towards advance directives and end of life care as well as professional.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Sample Size</th>
<th>Description</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scherer (2006) (Scherer et al., 2006)</td>
<td>USA</td>
<td>210/1000 critical care nurses</td>
<td>Nurses scores were highest for the subscale assessing general knowledge of advance directives, including definitions, the role of proxy decision makers and some legal issues related to advance directives. For this subscale the mean score was 7.07 out of a possible 10 (70.7%).</td>
<td>High level of agreement that it is appropriate to give medication to relieve pain even if it may hasten a patient’s death. The qualitative component outlined the need for 1) education regarding advance directives, 2) the need for more time to assist patients completing advance directives, 3) support from administrators and physicians regarding the nurse’s role in helping patients complete advance directives.</td>
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<td>Most respondents (94.8%) agreed that nurses should uphold a patient’s wishes even if the wishes conflict with the nurses’ own view.</td>
<td>Most of the respondents had cared for a patient who had advance directives (98.0%), counselled patients and patients’ families about advance directives (84.8%), and initiated discussion with patients about advance directives (82.9%).</td>
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<td>The respondents felt strongly (96.1% agreement) that patients should receive the pain medication they need even though the medication may hasten death.</td>
<td>48.1% of nurses had provided treatment to a patient whose advance directive had indicated otherwise. 71.3% of nurses had witnessed others providing treatment to a patient whose advance directive had indicated otherwise.</td>
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<td>Agreement was high that nurses are responsible for conferring with a physician if a patient’s rights have not been considered.</td>
<td>59.1% agreed nurses often have insufficient time to discuss advance directives with patients. Only 12.6% believed that nurses spend enough time discussing advance directives with patients.</td>
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<td>96.2% agreed that nurses should help inform patients of their experiences with advance directives.</td>
<td>Respondents were most confident (scores &gt;4) on items dealing with confidence in initiating (mean score 4.06, SD 1.05) and answering patients’ (mean score 4.03, SD</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Findings</td>
<td>Notes</td>
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<tr>
<td>Duke (2007) (Duke et al., 2007)</td>
<td>USA</td>
<td>108/283 nurses</td>
<td>Only 7% were aware of competency requirements for an advance directive. 80% felt advance directives were helpful. 56% had assisted a patient with an advance directive.</td>
<td>Small sample size. In the open-ended question 3 respondents expressed concerns that wishes would not be honoured by physicians and/or families. 42% incorrectly thought that nutrition and hydration were included in comfort care.</td>
</tr>
<tr>
<td>Jezewski (2007) (Jezewski &amp; Feng, 2007)</td>
<td>USA</td>
<td>579/3800 emergency nurses</td>
<td>Nurses scores were highest for the subscale assessing general knowledge of advance directives including definitions, the role of proxy decision makers and some legal issues related to advance directives. For this subscale the mean score was 6.8 out of a possible 10 (68%).</td>
<td>Non-probability sampling. Over 76% answered yes to having cared for a patient with an advance directive, read their institutional policies/procedures concerning advance directives, and initiated discussion about advance directives with a patient. High level of agreement that nurses should uphold the patient's wishes even if they conflict with the nurse's own view. High level of agreement that nurses should help inform patients about their condition and treatment alternatives. 40% of the nurses had provided treatment to patients whose advance directive indicated otherwise and 63% of the nurses in the study had observed others providing treatment to patients whose advance directive indicated otherwise. 83% of nurses surveyed agreed that the presence of an advance directive Only 10% believed that nurses spend enough time discussing advance directives with patients. Low internal consistency for attitudes to advance directives and EoL decision making. Also, there was low internal consistency for the subscale asking about opinions based on professional experiences with advance directives.</td>
</tr>
<tr>
<td>Putman-Casdorph (2009) (Putman-Casdorph et al., 2009)</td>
<td>USA</td>
<td>87/198 acute care nurses (general medical / surgical, cardiac) &amp; inpatient &amp; outpatient oncology nurses</td>
<td>Participants scored highest on general questions related to advance directives such as questions about the purpose and function of living wills and medical power of attorney, with 95% to 100% of participants answering those questions correctly.</td>
<td>Participants responded with moderately negative attitudes overall toward advance directives, with an aggregate mean score of 2.21 (SD = 0.84) and a range from 1 to 5. Higher mean scores were consistent with more positive attitudes.</td>
</tr>
<tr>
<td>Zhou (2010) (Zhou et al., 2010)</td>
<td>USA</td>
<td>89/300 oncology advanced practice nurses</td>
<td>The average score of all respondents who answered the 12-item knowledge section correctly was 67% (range 33%-92%), whereas the majority of respondents (88%) achieved greater than a 50% correct score.</td>
<td>In general, respondents scored positively in their attitudes toward advance care planning (mean = 1.91, SD = 0.37, range 1.5-2.52). Lower scores were consistent with positive attitudes.</td>
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</table>

When asked about whether they had advance care planning discussions with 50% or more of patients with advanced cancer in their practice, responses varied greatly (mean = 3.04, SD = 1.02). Lower scores represent positive behaviour.

When asked about how often their collaborating oncologist(s) initiated advance care planning discussions, 44% said “sometimes,” and 37% said “often” (answer key = never, rarely, sometimes, often, always, don’t know).

Oncology APNs working at different practice settings may have different patient care foci. For example, APNs not involved in direct patient care or already working in hospice may not need to practice advance care planning.

Reliant on self-reporting.
Because advance care planning is a value-laden practice, social desirability bias also may have influenced respondents’ choices to certain survey items.

**Snyder (2013) (Snyder et al., 2013)**

- **Location**: USA
- **Participants**: 158/372 primary care physicians
- **Findings**:
  - Many physicians felt that it was the patients and/or families themselves who erect barriers to successful advance care planning discussions.
  - 44% percent of primary care physicians expressed the opinion that advance care planning discussions take too much time.
  - Physicians report discussing advance directives with only 43% of the patients they identified as having progressive, chronic life-limiting disease and only 61% of patients who are terminally ill.

**Sellars (2015) (Sellars et al., 2015)**

- **Location**: Australia
- **Participants**: 178/962 home care package case managers
- **Findings**:
  - 97.5% of physicians expressed comfort in discussing advance care planning.
  - 75% believed advance care planning was valuable and worthwhile for clients.
  - 74% believed clients were more comfortable discussing advance care planning and EOL care in their own home.
  - 70% had initiated an advance care planning conversation in the previous 12 months, but 80% of the conversations did not progress to documentation of wishes.
  - 65% were not satisfied with the time allowed to undertake advance care planning, 60% with lack of support from senior staff, 67% with the lack of appropriate documentation for recording outcomes, 78% with the lack of training and 72% with the lack of written material to give to service users and their families.

Poor response rate.

Only representative of single geographic region.

No questions asking about knowledge of advance care planning were asked.

Reliant on self-reporting.
55% of case managers believed that they had a role in advance care planning. Only 27% believed that the majority of clients were interested. Risk of social desirability bias.

66% felt comfortable discussing advance care planning with clients. Only 12% reported having a negative experience of advance care planning.

Only 48% (n=85) had previously completed any advance care planning training and only 30% (n=25) had that funded by their employer.

<table>
<thead>
<tr>
<th>Beck (2017) (Beck et al., 2017)</th>
<th>Ireland</th>
<th>116/178 nursing home managers</th>
<th>The results demonstrated that nursing home managers’ knowledge of advance care planning was poor, with less than half the sample (47% n = 54) being able to respond correctly to more than three of the seven knowledge questions.</th>
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<tbody>
<tr>
<td>Respondents highlighted the difficulty for nursing home managers in discussing death, with one participant stating ‘death is a tough subject’.</td>
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<tr>
<td>Less than half of nursing home managers perceived it to be their role (47% n = 54)</td>
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<tr>
<td>Self-reporting means that accuracy of information is a concern.</td>
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</table>

Advance care planning was viewed incorrectly as a legally binding document (41% n = 48), related only to medical interventions (50% n = 58) with little recognition of the voluntary nature of the process.

Barriers to advance care planning identified included:

1) lack of knowledge
2) time constraints
3) family conflict and the desire to protect the person from harm.

Those who had attended specific advance care planning training (24% n = 28) did not have improved knowledge as a result but they were likely to have a more positive attitude towards advance care planning.

Acknowledged risk of response bias.

There was an assumption that people with dementia (81% n = 94) do not want to
| **Know about future care options.** | **A considerable proportion of respondents also perceived that advance care planning may also impact negatively on a resident's sense of hope (34% n = 39)** | **Only represents single geographic region in UK.** |


**Table 2 Description of questionnaire development for Knowledge, Attitudes and Practice studies included in the review**

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<tbody>
<tr>
<td>New instrument developed by author. Based on literature review and using 9 questions from a previous piece of work ‘Medical Consent Act’ survey.</td>
<td>New instrument developed by author. Amalgamated 3 previously used questionnaires as well as new author developed items.</td>
<td>New instrument developed by author. Unclear how it was developed.</td>
<td>New instrument developed by author. Based on literature on the attitudes and practices of nursing personnel regarding advance directives, round table discussion with practicing nurses and the legislative mandates found in the PSDA and in Texas laws on advance directives.</td>
<td>New instrument developed by author. Developed using Azjen’s ‘Theory of Planned Behaviour’ as theoretical base. Questions were taken from previously developed surveys, developed using author’s experience as Oncology APN and several hospice and palliative experts recommendations.</td>
<td>New instrument developed by author. Unclear how it was developed.</td>
<td>New instrument developed by author. Based on literature and authors previous research.</td>
<td>The Zhou instrument was adapted to fit with the different context of care home managers.</td>
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<tr>
<td>How many items were in the instrument?</td>
<td>Not provided. Described as 12-page survey.</td>
<td>52</td>
<td>115</td>
<td>40</td>
<td>52</td>
<td>30</td>
<td>46</td>
<td>48</td>
</tr>
<tr>
<td>What were the type of quantitative</td>
<td>True / False</td>
<td>True / False</td>
<td>Yes / No / Don’t know</td>
<td>Not reported.</td>
<td>Multiple choice</td>
<td>Multiple choice</td>
<td>Multiple choice</td>
<td>True / False / Don’t know</td>
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<tr>
<td>questions used?</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Likert scales</td>
<td>Likert scales</td>
<td>Asked to provide a percentage</td>
<td>Likert scales</td>
<td>Likert scales</td>
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<td>Unknown number of open-ended questions.</td>
<td>2 open-ended questions.</td>
<td>1 open ended question.</td>
<td>7 open-ended questions.</td>
<td>1 open-ended question.</td>
<td>None.</td>
<td>3 open-ended questions.</td>
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<tr>
<td>How was validity established?</td>
<td>Content validity and clarity were assessed by a multidisciplinary panel of experts (lawyer, nurse, social worker). The modified survey was evaluated for content validity by topic experts (two nurse-attorneys, one attorney specializing in elder law, and five nurses)</td>
<td>Content validity was established by 7-person panel consisting of experts in gerontology, palliative care and/or dementia.</td>
<td>Content validity established by 6-person panel of experts in gerontology, palliative care and/or dementia.</td>
<td>Content validity established by panel of 3 academic researchers and palliative care experts from several academic and clinical institutions.</td>
<td>Content validity established by panel of 3 academic researchers and palliative care experts from several academic and clinical institutions.</td>
<td>Not established.</td>
<td>Not established.</td>
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</tr>
<tr>
<td>Question</td>
<td>Test-retest for knowledge questions in pilot study. Cronbach's alpha was used for the entire study sample for the attitude questions.</td>
<td>Test-retest of the pilot survey was conducted and Cronbach's alpha was used to establish internal consistency (this was measured separately for each component part).</td>
<td>Internal consistency was calculated (unclear which technique was used).</td>
<td>1) Factor analysis performed, and 5 different factors found. 2 related to practice and 3 related to attitudes. Cronbach's alpha used to demonstrate internal consistency within these 5 factors. 2) Test-retest reliability for a subsample (53) and correlation coefficient calculated using Pearson's R.</td>
<td>Internal consistency calculated using Cronbach's Alpha for knowledge and attitude sections.</td>
<td>Not measured.</td>
<td>Internal consistency calculated using Cronbach's Alpha.</td>
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Table 3 Quality assessment of methodology of articles included in the review

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<tr>
<td><strong>Title and Abstract</strong></td>
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<tr>
<td>Is the design of the study design reported in the title and/or abstract?</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Either title or abstract</td>
<td>Both title and abstract</td>
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<tr>
<td><strong>Introduction</strong></td>
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<tr>
<td>Is there an explanation of why the research is necessary, placing the study in context of previous work in relevant fields?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Is the purpose or aim of the paper explained?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td><strong>Methods</strong></td>
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<td>Research Tool</td>
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<tr>
<td>Is the questionnaire described?</td>
<td>Questionnaire provided</td>
<td>Core questions provided</td>
<td>Core questions provided</td>
<td>Core questions provided</td>
<td>Core questions provided</td>
<td>Core questions provided</td>
<td>Core questions provided</td>
<td>Questionnaire provided</td>
<td>Questionnaire provided</td>
<td>Questionnaire provided</td>
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<tr>
<td>If existing tool - Are its psychometric properties presented?</td>
<td>N/A</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
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<td>N/A</td>
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<tr>
<td>If existing tool - Are references to the original work provided?</td>
<td>N/A</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>New tool - Are the procedures used to develop and pre-test it reported?</td>
<td>Develop only</td>
<td>N/A</td>
<td>Pre-Test only</td>
<td>N/A</td>
<td>Develop only</td>
<td>N/A</td>
<td>Both</td>
<td>Neither</td>
<td>Develop only</td>
<td>Both</td>
</tr>
<tr>
<td>New tool - Have its reliability and validity been reported?</td>
<td>Validity only</td>
<td>Both</td>
<td>Both</td>
<td>N/A</td>
<td>Both</td>
<td>N/A</td>
<td>Both</td>
<td>Reliability only</td>
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</tr>
<tr>
<td>Is a description of the scoring procedures provided?</td>
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<td>N/A</td>
<td>N/A</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
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</table>

**Sample Selection**

<table>
<thead>
<tr>
<th>Is there a description of the survey population and the sample frame used to identify this population?</th>
<th>Both</th>
<th>Both</th>
<th>Both</th>
<th>Both</th>
<th>Both</th>
<th>Both</th>
<th>Sample frame</th>
<th>Sample frame</th>
<th>Both</th>
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<tbody>
<tr>
<td>Do the authors provide a description of</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
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</table>

43
| How representative the sample is of the underlying population? |   |   |   |   |   |   |   |   |   |
| Is a sample size calculation or rationale/justification for the sample size reported? | Yes | Yes | Yes | Yes | No | Yes | No | No | No | Yes | No |

**Survey Administration**

<p>| Is the mode of administration reported? | Mail | Mail | Mail | Mail | In person - self administered | Mail | Mail | Online | Mail | Online | Mail |
| Do the authors provide information on the type of contact and how many attempts were made to contact subjects (i.e., prenotification by letter or telephone, reminder postcard, duplicate questionnaire with reminder etc.)? | Type and number | Type and number | Type and number | Type only | Type only | Type only | Type and number | Type and number | Type only | Type and number | Type and number |</p>
<table>
<thead>
<tr>
<th>Do the authors report whether incentives were provided (financial or other)?</th>
<th>Not Reported</th>
<th>Yes, Incentive provided,</th>
<th>Not Reported</th>
<th>Not Reported</th>
<th>Not Reported</th>
<th>Yes, Incentive provided</th>
<th>Yes, Incentive provided</th>
<th>Not Reported</th>
<th>Not Reported</th>
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<tbody>
<tr>
<td>If reported, what incentive was provided.</td>
<td>Not Reported</td>
<td>50¢ donation to charity for each completed questionnaire</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td>$10 gift card</td>
<td>$25 gift certificate</td>
<td>Not Reported</td>
</tr>
<tr>
<td>Is there a description of who approached potential participants [e.g., identification of who signed the covering letter]?</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Analysis</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Is the method of data analysis reported?</td>
<td>Adequate</td>
<td>Adequate</td>
<td>Adequate</td>
<td>Adequate</td>
<td>Adequate</td>
<td>Adequate</td>
<td>Adequate</td>
<td>Inadequate</td>
<td>Adequate</td>
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</tr>
<tr>
<td>Do the authors provide methods for analysis of nonresponse error?</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Is the method for calculating</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>response rate provided?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>------------------------</td>
<td>---</td>
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<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Are definitions provided for complete versus partial completions?</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
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</tr>
<tr>
<td>Are the methods for handling item missing data reported?</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
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</table>

**Results**

<table>
<thead>
<tr>
<th>Is the response rate reported?</th>
<th>Yes, defined</th>
<th>Yes, defined</th>
<th>Yes, defined</th>
<th>Yes, defined</th>
<th>Yes, not defined</th>
<th>Yes, defined</th>
<th>Yes, defined</th>
<th>Yes, defined</th>
<th>Yes, defined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are all respondents accounted for?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Is information given on how non-respondents differ from respondents?</td>
<td>Issue addressed</td>
<td>No information</td>
<td>No information</td>
<td>No information</td>
<td>No information</td>
<td>No information</td>
<td>Issue addressed</td>
<td>Issue addressed</td>
<td>No information</td>
</tr>
<tr>
<td>Are the results clearly presented?</td>
<td>Yes, partial</td>
<td>Yes, partial</td>
<td>Yes, complete</td>
<td>Yes, partial</td>
<td>Yes, complete</td>
<td>Yes, partial</td>
<td>Yes, complete</td>
<td>Yes, complete</td>
<td>Yes, complete</td>
</tr>
<tr>
<td>Do the results address the objective(s)?</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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**Discussion**


<table>
<thead>
<tr>
<th>Are the results summarized with reference to the study objectives?</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
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</thead>
<tbody>
<tr>
<td>Are the strengths of the study stated?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Are the limitations of the study (taking into account potential sources of bias or imprecision) stated?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td>Is the generalisability of the study results discussed?</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
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**Ethical Quality Indicators**

<table>
<thead>
<tr>
<th>Study funding reported?</th>
<th>No</th>
<th>No</th>
<th>No</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Research Ethics Board (REB) review reported?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Reporting of subject consent procedures?</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
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<td>No</td>
</tr>
</tbody>
</table>

**Summary Score (Good = >75% of criteria met; Moderate = 50-75% of criteria met; Poor = <50% of criteria met)**

<p>| Percentage Score | 63% | 81% | 72% | 73% | 56% | 68% | 65% | 74% | 65% | 67% | 74% |</p>
<table>
<thead>
<tr>
<th>Rating</th>
<th>Moderate</th>
<th>Good</th>
<th>Moderate</th>
<th>Moderate</th>
<th>Moderate</th>
<th>Moderate</th>
<th>Moderate</th>
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<th>Moderate</th>
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</thead>
</table>