Advance care planning (ACP) and End of Life (EoL) discussions in the perioperative period: a review of healthcare professionals' knowledge, attitudes and training.

ACP and EoL discussions in the perioperative period

Douglas H. Blackwood[1*]

Cecilia Vindrola-Padros[2]

Monty G. Mythen[1,3]

David Walker [1,4]

[1] Department of Anaesthesia and Perioperative Medicine, University College London Hospitals, London, UK

[2] Department of Applied Health Research, University College London (UCL), London, UK

[3] National Institute of Health Research Biomedical Research Centre, London, UK

[4] Centre for Anaesthesia & Perioperative Medicine, University College London (UCL), 2nd Floor, Charles Bell House, 43-45 Foley Street, London, UK, W1W 7TS

[*] Correspondence to Dr Douglas H. Blackwood, Centre for Anaesthesia & Perioperative Medicine, University College London (UCL), 2nd Floor, Charles Bell House, 43-45 Foley Street, London, UK, W1W 7TS

E-mail douglas.blackwood@nhs.net

Summary

Whilst the risk of dying following an operation in the U.K is very small the volume of surgery means that there are 20-25,000 deaths each year. For these patients, and others who suffer major complications, critical illness often leads to a loss of capacity. If wishes are not discussed in advance the patient may be excluded from meaningful involvement in decisions affecting their care. The preoperative period has been postulated as one where advance care planning could begin by engaging in voluntary conversations about an individuals' wishes, priorities and values should they lose capacity.

There remain unanswered questions as to whether healthcare professionals are supportive of a move towards better engagement in such discussions with patients. Even if the reception to the idea is positive it is clear that appropriate training and understanding will be required. The aims of this review are to describe the current knowledge and attitudes of healthcare professionals towards advance care planning in the perioperative setting and to outline any educational programmes or training limitations which have been identified.

7 articles were identified which met the inclusion criteria. They indicate that healthcare professionals mostly have a positive view of advance care planning in the perioperative period and there is little training or educational content available. Despite this, most healthcare professionals report feeling well equipped to have such discussions. Evidence was not found of advance care planning becoming a routine part of training or practice in the care of patients in the lead up to high-risk surgery.

Key Words

Advance Care Planning

Health Personnel

Perioperative Care

Introduction

A current drive within healthcare is towards more patient involvement and greater shared decision making between healthcare professionals (HCPs) and their patients. The recent launch of 'Choosing Wisely UK'[1] aims to improve the conversations HCPs have with patients by focussing discussions on the impact of particular interventions on individual patients as opposed to a generic list of risks and benefits. In 2015, the Royal College of Anaesthetists published its agenda 'Perioperative Medicine: The Pathway to Better Surgical Care'[2], which outlined the desire to deliver surgical care which is holistic and focuses on the individual, their co-morbidities, concerns and wishes, and not solely the operation and the index disease being treated.

Advance care planning (ACP) has an important role in shared decision making for patients who have significant illness or who are known to be coming towards the end of life. It has been defined as a voluntary discussion between a patient and his/her care provider(s) and family, outlining a person's values, goals and concerns as well as any preferences for particular treatments[3]. The General Medical Council (GMC) defines *'nearing end of life'* as those patients considered to be within their last year of life[4]. Whilst, in practice, this cohort may be difficult to identify, where possible, offering patients the opportunity to discuss important personal issues is considered an important care quality improvement.

In England and Wales, 'advance statements' outline general principles to make best-interest decisions whilst 'advance decisions to refuse treatment' are legally binding as per the Mental Capacity Act (2005)[5]. In the USA, the different states exhibit a great deal of variability in advance planning law and policy[6] and, similarly across the world, law, terminology, documentation and uptake differ significantly. For the purposes of this review ACP will be used to describe the process of discussion, which may or may not result in a written document, and the term Advance Directive (AD) shall refer to any documentation of values, goals, concerns and/or preferences. Most ADs will be legally binding, but this is dependent on the format and jurisdiction in which they are produced and/or actioned. 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 AD[7].

The reality of critical illness is that it often results in the loss of capacity and an AD may offer guidance for clinicians and family members to understand what the patient would wish for themselves at such times[8]. For those patients who have significant complications following surgery, including those which may ultimately prove fatal, unless they have discussed their wishes in advance, their loss of capacity may preclude them from any meaningful involvement in the decisions affecting their care[8]. Family members are encouraged to be a part of the ACP process, at the patient's discretion[9 10], and a systematic review in 2014 found three studies which showed an association between ADs and a decrease in family concerns, stress and learned helplessness[11] following the death of a family member.

It has been established that there exists a high risk surgical population that whilst accounting for only 12.5% of operations is responsible for >80% of perioperative deaths[12]. This group is

characterised by older patients with more co-morbidities and they have both greater mortality and rates of complications post-operatively[13]. Given an ageing population[14] with an increasing number of comorbidities[15] as well as rising levels of surgery in patients who would previously have been thought not suitable[16], it is probable that the number of high risk patients undergoing surgery will increase in the future. In 2015, we published an editorial[17] arguing that given the persistence of this high risk surgical population it would be valuable to utilise perioperative encounters to begin the process of a voluntary, patient discussion documenting a patients' hopes and aspirations for the planned treatment ahead, including, where appropriate, end of life (EoL) care via ACP.

We have conducted this systematic review to identify the knowledge and attitudes of HCPs towards ACP prior to surgery and to outline any examples of current practice or barriers to delivery. It includes studies which collected data directly from HCPs regarding ACP and to our knowledge, this is the first review to explore this topic in the perioperative setting.

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[18]. A review protocol was registered in PROSPERO: registration number CRD42017052595.

Research questions

The review was guided by the following questions:

1. What is the attitude of HCPs towards having EoL and ACP conversations with patients in the perioperative setting? How confident are HCPs in having such conversations?
2. What is the level of knowledge reported by HCPs involved in perioperative care with regards to having EoL and ACP conversations in the perioperative setting?
3. What are the knowledge and training limitations identified by HCPs involved in perioperative care with regards to having EoL and ACP conversations in the perioperative setting?
4. Are there any interventions (i.e. educational programmes) currently being designed or used to train those involved in perioperative care to have EoL / ACP discussions with patients?

Search Strategy

The authors, one social scientist (CVP) and three clinicians (DB, MM and DW), conducted a review of peer-reviewed journal articles using multiple databases in January and February 2017: MEDLINE, Embase, CINAHL Plus, Web of Science and Proquest Central. Additionally, a grey literature search was carried out using the databases: OpenGrey and Trip. We used the Population-Intervention-Comparison-Outcomes-Setting (PICOS) framework[19] to develop our search strategy (Table 1). The search used a combination of keywords and subject headings for the concepts of advance care planning and perioperative medicine where appropriate. An example search strategy can be found in Appendix 1. 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, abstract and full text) based on the following criteria:

1. Focussed on the knowledge, attitudes or training of healthcare practitioners who have end of life and ACP discussions with patients.
2. These conversations were pre-emptive and occurred within the 'perioperative period'.

The perioperative period was defined as *'the moment from which the decision to undergo surgery has been taken until the patient has returned to best health and no longer requires specialist input'*

(adapted from RCOA document 'Perioperative Medicine: The pathway to better surgical care'[2]). The healthcare practitioners considered relevant for the perioperative period were:

1. Surgeons
2. Anaesthetists / anaesthesiologists
3. Critical care physicians
4. Orthogeriatricians
5. Any other involved in the perioperative period

Data extraction

The included articles were analysed using a data extraction form developed in Microsoft Excel. The categories used in the data extraction form are summarised in Appendix 2. The form was developed after the initial screening of full-text articles.

Data synthesis

Data were exported from the spreadsheet and the main article characteristics were collated. The authors also identified emergent themes and analysed them in relation to the research questions.

Quality assessment

The methodological quality of the studies was critically appraised using the Mixed Methods Appraisal Tool (MMAT)[20–22]. Two of the authors (DB and CVP) rated the articles independently. The raters discussed their responses until agreement was reached and inter-rater reliability was calculated using the kappa statistic[23].

Results

Identification of studies

The initial search yielded 1,998 articles (76 from CINAHL, 318 from EMBASE, 297 from ProQuest, 723 from PubMed, 144 from Web of Science, 7 from OpenGrey and 433 from Trip). Once duplicates were removed, there were a total of 1,566 articles. These were screened based on title of article, resulting in 124 (Figure 1). Screening based on abstracts left 22 articles for full text review. Screening of the full texts led to 6 articles meeting the inclusion criteria. Following review of the references of the articles which met the inclusion criteria, a further 1 article was included. Thus, the final review included 7 articles.

No limits to language or date of publication were applied to the search. We did not restrict the article selection based on the type of study design. We excluded articles that focussed on reactive discussions (e.g. withdrawal of life sustaining treatment or terminal diagnoses), as opposed to pre-emptive discussions (i.e. prior to a patient's deterioration or having a complication).

Study characteristics

The characteristics of the 7 studies included in the review are presented in Table 2. All articles originated in either the United States (five) or Switzerland (two). Despite searching the grey literature no articles were found which met the inclusion criteria.

The majority of studies had quantitative designs (six) and one was qualitative. The most common quantitative data collection method was a self-administered survey, either online or on paper. One quantitative study used self-scoring and scoring from standardised patients following Objective Structured Clinical Examination (OSCE) scenarios. The qualitative study used semi-structured interviews.

Surgeons or surgical trainees were participants in all the studies (seven). Other specialists included in some of the studies were: anaesthetists (two), general practitioners (two), physicians (two) and intensivists (two).

Quality Assessment

The scores from the quality assessment are presented in Table 2. Only one study covered all of the criteria included in the appraisal tool. Inter-rater agreement was 83%, with a Cohen's kappa of 0.67, which indicates substantial agreement.

Attitudes of HCPs towards ACP

Four studies (2 from USA and 2 from Switzerland) investigated the attitudes held by HCPs involved in the perioperative care of patients towards ACP and ADs. Two studies[24 25] (1 Switzerland, 1 USA),

reported that physicians felt that ADs were useful, however, for some there was concern that the inherent ambiguity of ADs meant there could be conflict between the drive for surgical cure and the treatment limitations that are intrinsic to ADs[25] (USA). There was also concern expressed that the topic could induce fear or unease in patients[24] (Switzerland).

One study[26] (USA) looking at surgical trainees found that only 19% thought that attending physicians viewed treating the psychosocial needs of patients as a core clinical competency and only 12% thought their attending physician viewed ACP as a routine part of care.

Two studies[25 27] (USA and Switzerland) asked which speciality should be having these discussions with patients. There was no consensus although some HCPs expressed the opinion that it should be someone with a longstanding relationship with the patient[25 27] (USA and Switzerland). No intensivists who were asked rated their speciality to be best placed to have such discussions and there was no mention of anaesthesia as the appropriate specialty[27] (Switzerland).

One study[27] (Switzerland) asked about the timing of ACP and EoL conversations and found 42% felt that before major surgery was the optimal time to have such discussions.

Knowledge of HCPs about ACP

Five of the articles looked at how physicians appraised themselves in terms of their knowledge of, preparedness or ability to have ACP or EoL conversations with patients in the perioperative setting. Three studies[26–28] (2 from USA, 1 from Switzerland) reported self-scoring of HCPs and all found that individuals rated themselves highly in terms of preparedness and skill in having such discussions. One study[24] (Switzerland) found that 14% of respondents had never heard of ACP and that 44% would avoid having ACP conversations due to a lack of knowhow. Another[29] (USA) found that 92.9% of respondents felt that elderly patients would often undergo surgery without adequate discussion about how surgery would impact their quality of life.

Training Limitations

Five studies identified educational or training gaps and limitations for HCPs. Two studies[26 28] (USA) found a majority of trainees were never observed having ACP and EoL discussions by an attending physician and never received feedback. Another[30] (USA) found that only around 1/3 of respondents felt the surgical curriculum contained sufficient education with regards to communication, end of life and palliative care issues. Finally, one study[29] (USA) found that only 10% of respondents had received formal consent training.

Educational Interventions

One study[28] (USA) described a difficult conversation OSCE with standardised patients which was used for both junior and senior surgical residents. The study described performance of candidates in the OSCE and as such did not include validation or evaluation of the OSCE itself. Therefore, it is not possible to comment on its validity or effectiveness.

Discussion

It has been estimated that there are 20 – 25,000 deaths in the perioperative period in the UK each year[31] and many more life changing major complications. It is likely that these patients, their families and HCPs would have benefited from a discussion about the patient's wishes in the event of an unintended consequence of surgery in the perioperative period. Importantly the benefit of such discussions would not be limited to those patients who ultimately die, early conversations about priorities of care for patients undergoing surgery would help influence and direct their treatment to that which is right for them.

The most striking finding of this systematic review is the paucity of evidence. Despite having broad search terms and including grey literature, we were only able to find 7 articles which met our inclusion criteria. None of these articles originated from the UK, and given the social, attitudinal and legal differences between the UK, North America and Europe it may not be possible to transpose all of these findings to a UK context. One question this raises is whether the lack of UK data represents a lack of ACP or a lack of reporting in the literature. A 2005 survey found only 8% of the UK population had any form of AD[32] whilst in North America it is >30%[33 34]. This would suggest ACP is less established within the UK and this may be the reason for a lack of UK data.

From the information that was available, HCPs tended to have a positive opinion towards ACP when asked. However, it was believed that this view was not always shared with their colleagues and, in particular, by senior surgeons[26 28]. It has previously been described how surgeons can require a commitment from patients to undergo often burdensome post-operative therapy and that they may see treatment limitations as a lack of that necessary commitment[35 36]. A partial answer to this may be a redesign of ACP specifically for the surgical setting. These may focus on ultimate outcomes as opposed to treatment limitations allowing for more flexibility for the perioperative team. Current advice surrounding DNACPR orders at the time of surgery explains that in almost all cases they require either suspension or modification to allow surgery to proceed[37] and this highlights the necessity for more bespoke ACP for the perioperative period.

Family practitioners were commonly cited as being best placed to lead such discussions given their long-standing relationship with the patient however this relationship is not universal. Additionally, they may lack the necessary knowledge of surgery and critical illness to make this an effective discussion about the associated risks and potential outcomes. As the role of perioperative medicine evolves it may be these HCPs who have the correct understanding of risk stratification tools, post-operative complications as well as the appropriate amount of time to have these discussions. If this is desirable, it will require significant effort and cultural change. This review has demonstrated an absence of anaesthesia and intensive care being considered as leading specialties in the delivery of ACP, both by their own practitioners, and other specialties.

This review identified that HCPs tended to rate themselves highly in terms of their knowledge and preparedness to engage with ACP, although this was not unanimous. The studies which reported a high degree of knowledge were mostly conducted on trainee doctors and this may reflect a greater

emphasis on communication in the medical curriculum in recent years[38]. All of these studies relied on the inherent bias of self-scoring and thus may not accurately capture true knowledge levels. As most studies focused on trainee doctors, the self-scoring may be unreliable as trainees, by definition, lack the expertise and experience of more senior clinicians. Nonetheless, the one study which included an OSCE scenario using simulated patients did demonstrate a high level of successful patient conversations alongside self-reporting of good knowledge. Despite the high levels of knowledge and supportiveness reported, one study[29] found that 92% of respondents thought elderly patients would often undergo surgery without adequate discussion about its potential impact. This finding is discouraging as it implies that, despite HCPs reporting support and adequate knowledge and skills to perform ACP, it is apparently absent from routine clinical practice.

In all articles in which training was mentioned there was concern over the type and quality on offer. A lack of observation and feedback was frequently described as well as an absence of formal training. Only one educational intervention was discovered which partially looked at the pre-emptive discussions that were the focus of this review. The importance of feedback and the role of simulated patients were described as early as the 1970's[39] and, recently, there has been a proliferation of end of life care communication skills training interventions[40]. These include role-play, group work and reflection and discussion as well as the more traditional lectures and presentations[40]. This model would seem appropriate for perioperative ACP conversations although the content would need to be adapted for the particular challenges and nuances of the perioperative setting. The fact that most HCPs reported positive attitudes towards the development of ACP provides hope that educational interventions for improvement would be embraced.

This review should be interpreted with its limitations in mind. The literature search was carried out in January and February 2017 so any articles published after this date are not included. Additionally, although we used multiple broad search terms it is possible that we missed articles that did not use these terms. This was evident in the fact that we found an additional article during our review of the references of the articles, which met the inclusion criteria. Our review included studies of multiple designs and methodologies making it difficult to draw overall general conclusions. The quality assessment found that the studies were of variable quality with only one covering all of the criteria covered by the appraisal tool. Five of the articles were survey based. A common limitation in survey research is sampling bias, where respondents who take part in the survey are only those who have some interest in the subject, which may lead to skewed results. One of the aims of the review was to capture interventions in the form of educational programmes being used to provide training on having EoL or ACP discussions with patients. Most educational programmes are not published in peer-reviewed journals. We tried to account for this following strategies used by other reviews on education for HCPs such as the inclusion on grey literature[41], but we may have still missed educational programmes on this topic.

The expectations of professional bodies and governments are for HCPs to promote and utilise ACP and ADs with their patients[424]. Despite this, there remain unanswered questions and a paucity of evidence to guide ACP generally and, as demonstrated by this review, specifically in the perioperative setting. There is some evidence of support for ACP within the public[43] and for ACP resulting in the decreased use of life sustaining treatment, but this could at best be described as

limited[11]. There is little in the literature to guide how best to have ACP conversations, which profession / specialty should take the lead or whether patients agree that HCPs are as good at these conversations as their self-reported scoring suggest. All of these areas require further elucidation if we are to make shared decision making at end of life a reality.

Conclusion

In an age of shared decision making, the most striking finding of this review is the paucity of evidence to guide ACP in the perioperative setting. The evidence that was available indicated that HCPs have a mostly positive view of the concept of ACP and EoL discussion in the perioperative period, but that there is little training or educational content available. Despite this, most HCPs report feeling well equipped to have such discussions. We did not find evidence of ACP becoming a routine part of training or practice in the care of patients in the lead up to high-risk surgery. In keeping with the 'Choosing Wisely UK' and perioperative medicine agendas, this is something that may be developed in the future. In order to make this a reality, significant investment in creating validated educational content and resources will be required.

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.

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Table 1.

Population	HCPs involved in the perioperative care of patients; this will include anaesthetists (anesthesiologists) and surgeons but may also include critical care physicians, orthogeriatricians or others involved during the perioperative period.
Intervention	The levels of knowledge, attitudes towards and training of HCPs regarding ACP and EoL discussions with patient's in the perioperative setting. In particular, how comfortable and confident healthcare professionals are having these conversations.
Comparator	We would not expect a 'control' group given the nature of this review. It is possible that if educational programs are discovered they may have a comparator group consisting of those not exposed to the educational content.
Outcome	The primary outcome is to capture healthcare professionals' attitudes and knowledge in regard to ACP and EoL conversations in the perioperative period. A secondary outcome is to determine if there are any educational / training initiatives to help healthcare professionals with ACP and EoL discussions and to assess any gaps in education / training.
Setting	The perioperative period which will be defined as 'the moment from the decision to undergo surgery has been taken until the patient has returned to best health and no longer requires specialist input' (adapted from RCOA document 'Perioperative Medicine: The pathway to better surgical care'[2]).

Table 2.

Authors	Country	Study Design	Population	Data Collection Methods	Knowledge	Attitudes	Identified Educational Gaps & Limitations	MMAT appraisal score
Amini et al. (2014)	USA	Quantitative	59 / 125 hepatobiliary surgery fellows	Self-administered online survey	75% rated themselves as well or very well prepared to discuss EoL care decisions with a patient.	19% thought that attending physicians viewed treating the psychosocial needs of patients as a core clinical competency.	56.7% described never being observed having EoL conversations with patients by an attending physician.	***
						12% thought their attending physician viewed ACP as a routine part of care.	63.3% reported never receiving feedback on these conversations.	
Ayres et al. (2015)	USA	Quantitative	15 general surgery residents	Paper survey handed out at weekly academic meeting			26.6% agreed or strongly agreed the surgical resident curriculum contains an adequate amount of communication education.	**
							33.3% agreed there was adequate palliative care / end of life care education.	

Bradley et al. (2010)	USA	Qualitative	10 physicians caring for high risk surgical patients including surgeons, anaesthetists and intensivists	Semi-structured interviews		Respondents describe the benefit of ACP, specifically using the presence of an AD as a platform for discussions about the limitations of surgical therapy as well as a way to broach the possibility of limitations of life-supporting therapy postoperatively.		****
						Respondents expressed frustration with the inherent ambiguity of ADs and reported conflict between the drive for surgical cure and the treatment limitations that are intrinsic to ADs.		
						Some felt the ACP discussion should happen with somebody who has a longstanding relationship with the patient i.e. family physician.		
Falcone et al. (2014)	USA	Quantitative	27 senior surgery residents	OSCE stations with standardised patients (SP); self-scoring and formal scoring by SP.	Residents self-scored themselves as a mean of 5 on a 7 point Likert scale [4-6 IQR] as to whether they agree with the statement "I am trained to discuss this issue [goals of care] with patients".		Authors found that "despite frequently performing difficult communication tasks …, residents are not routinely observed by an attending physician". Only 29% of senior	***

					Residents self-scored themselves as a mean of 2 on a 7 point Likert scale [2-4 IQR] as to whether they agree with the statement "I feel nervous discussing this issue with patients".		residents said that had received feedback from a staff member.	
					Residents self-scored themselves as a mean of 5 on a 7 point Likert scale [4-6 IQR] as to whether they agree with the statement "I am skilled at this difficult conversation".			
Gigon et al. (2015) (Medicine)	Switzerland	Quantitative	164 physicians; mix of specialities including GP, Gen. Med., Cardiac, Intensivists	Paper survey mailed to respondents.	Physicians rated themselves as a mean of 8.1 (SD 2.1) / 10 when asked about their quality of communication (1 being poorest and 10 highest quality) to the statement "To involve the patient in the decisions about the treatments that he/she wants if he/she gets too sick to speak for him/herself". There was no statistically	In theory 82% of respondents would ask potential cardiovascular patients if they had an AD; 64% would ask for a copy for the medical notes; 51% would ask if it was still accurate.		***
						47% of respondents said they felt it was the GPs responsibility to start ACP conversations; 26% cardiologists; 19% internists; 2% intensivists.		

					significant difference between specialties.	No intensivists (0/22) rated their speciality to be the one to initiate ACP conversations; 61% of GPs felt they were best placed; 17% of cardiologists; 35% of internists.		
Gigon et al (2015) (Minerva Anestesiologica)	Switzerland	Quantitative	164 physicians; mix of specialities including GP, Gen. Med., Cardiac, Intensivists	Paper survey mailed to respondents.	14% had never heard of ACP.	85% of physicians felt ACP was useful.	44% of those who said they wouldn't have ACP conversations did so as they felt they had a lack of knowhow.	***
						77% would help a cardiovascular patient write an AD.	43% of physicians felt their information about ADs came from patients / colleagues / friends; post-medical school courses 42%; journals 29%; medical school 13%.	
						62% of those who said they wouldn't have ACP conversations did so as they felt the topic would induce fear in the patient; 47% that it would induce unease.		
						42% felt before major surgery was the optimal time to discuss ACP.		

Hadler et al (2016)	USA	Quantitative	69 anaesthetists and surgeons	Paper survey handed out at joint anaesthesia/surgery education case conference.	92.9% of respondents felt that sometimes or always an elderly patient would undergo surgery without adequate discussion about how surgery and post-op care would impact their QoL.	34% of respondents would confirm whether an AD was in place prior to taking a critically unwell patient to theatre.	10.1% of respondents said they had attended formal informed consent.	***

MMAT scores: **** indicates highest score