



Research Paper

Advance care planning in patients referred to hospital for acute medical care: Results of a national day of care survey

Thomas Knight^{a,*}, Alexandra Malyon^b, Zoe Fritz^c, Chris Subbe^d, Tim Cooksley^e, Mark Holland^f, Daniel Lasserson^a

^a Institute of Applied Health Research, University of Birmingham, United Kingdom

^b Cambridge University Hospital NHS Foundation Trust, United Kingdom

^c University of Cambridge, United Kingdom

^d School of Medical Sciences, Bangor University, United Kingdom

^e Manchester University NHS Foundation Trust, United Kingdom

^f School of Health and Social Care, University of Bolton, United Kingdom

ARTICLE INFO

Article History:

Received 1 July 2019

Revised 24 November 2019

Accepted 4 December 2019

Available online xxx

Key words:

Advance care plan

Emergency admission

Frailty

End-of-life care

ABSTRACT

Background: Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care provider. ACP is a key focus of national policy as a means to improve patient centered care at the end-of-life. Despite a wide held belief that ACP is beneficial, uptake is sporadic with considerable variation depending on age, ethnicity, location and disease group.

Methods: This study looked to establish the prevalence of ACP on initial presentation to hospital with a medical emergency within The Society for Acute Medicine Benchmarking Audit (SAMBA18). 123 acute hospitals from across the UK collected data during a day of care survey. The presence of ACP and the presence of 'Do Not Attempt Cardiopulmonary Resuscitation' orders were recorded separately.

Findings: Among 6072 patients presenting with an acute medical emergency, 290 patients (4.8%) had an ACP that was available for the admitting medical team. The prevalence of ACP increased incrementally with age, in patients less than 80 years old the prevalence was 2.9% (95% CI 2.7–3.1) compared with 9.5% (95% CI 9.1–10.0%) in patients aged over 80. In the patients aged over 90 the prevalence of ACP was 12.6% (95% CI 9.8–16.0). ACP was present in 23.3% (95% CI 21.8–24.8%) of patients admitted from institutional care compared with 3.5% (95% CI 3.3–3.7) of patients admitted from home. The prevalence of ACP was 7.1% (95% CI 6.6–7.6) amongst patients re-admitted to the hospital within the previous 30 days.

Interpretation: Very few patients have an ACP that is available to admitting medical teams during an unscheduled hospital admission. Even among patients with advanced age, and who have recently been in hospital, the prevalence of available ACP remains low, in spite of national guidance. Further interventions are needed to ensure that patients' wishes for care are known by providers of acute medical care.

© 2019 Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license.

(<http://creativecommons.org/licenses/by-nc-nd/4.0/>)

1. Introduction

More than half a million people die in the United Kingdom (UK) each year [1]. While some will die suddenly and unexpectedly the majority of individuals will experience a period of chronic illness, deteriorating health and live with increasing frailty before their death. In the UK, admission to hospital as an emergency is a prominent feature of the last 12 months of life. On average, patients are admitted three times during this period and spend almost 20 days in hospital as a result [2]. While an emergency admission might be necessary, it also reflects wider issues with the provision and planning of

end-of-life care. Advance care planning (ACP) is advocated as a means to improve quality of care, increasing the likelihood of individuals receiving care that reflects their preferences and is provided in their preferred environment, reducing the frequency of avoidable emergency admissions in the last months of life [3,4].

ACP is defined as a process “enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate” [5]. ACP should provide a comprehensive representation of a patient's wishes allowing treatment to be better tailored in situations where the capacity to participate in decision making is lost. The complexity of this process, potentially involving multiple interactions between patient, healthcare professionals and relatives over time can make communication of an

* Corresponding author.

E-mail address: thomasknight@nhs.net (T. Knight).

Research in context

Evidence before this study

Advance care planning (ACP) is a process of discussion about future care between an individual and their care provider. ACP increases the likelihood that care is delivered in accordance with a patient's prior wishes and communication of the outcome of ACP is essential in the acute care setting, where care providers are unfamiliar with a patient's history. ACP is recommended by national bodies but little is known about the availability of ACP decisions in the acute care setting.

Added value of this study

We report the first nation-wide survey of the availability of ACP to admitting medical teams following acute admission. Very few patients have an ACP that is available during an unscheduled hospital admission. Even among patients with advanced age, and who have recently been in hospital, the prevalence of available ACP remains low, in spite of national guidance.

Implications of all the available evidence

Further interventions are needed to ensure that patients' wishes for care are known by providers of acute medical care. Interventions which improve access to ACP for patients with multi-morbidity and frailty should be prioritised. Lack of initiation of ACP following acute admission is a missed opportunity to improve care in this patient population.

year following admission than patients under sixty [18]. If efforts to identify patients at an earlier stage of a disease process, and thus offer ACP, were effective, it would be expected that large numbers of patients would have ACP in place on initial presentation to hospital. However, little is known about the prevalence of ACP during emergency medical admissions. The Society for Acute Medicine Benchmarking Audit (SAMBA) is an annual audit identifying emergency medical admissions within a single twenty-four hour period which started in 2012 [19] and in 2018 recorded data from 123 acute hospitals in the UK [20]. This study aims to establish the availability of ACP on initial presentation to hospital with a medical emergency within SAMBA. We also looked see whether factors such as age or readmission within 30 days affected availability of ACP.

2. Methods

SAMBA18 was completed on Thursday 28th June 2018 between 00:00 and 23:59. Recruitment to SAMBA18 was open to all hospitals in the UK receiving acutely unwell medical patients. Non-acute and community hospitals were excluded from participating. There are no published data on the number of AMUs in the UK, therefore, the exact number of eligible units is unknown. The number of Type 1 Emergency Departments in the UK can be used to provide an approximation given all have provision to admit and manage acutely unwell medical patients. There are 236 type 1 Emergency Departments in the UK [21].

123 acute hospitals from across the UK collected data. All participating centres completed an online questionnaire to provide data on the local organisation and delivery of care as well as patient level data. Data was collected as early as possible (preferably within 12-h of admission) from clinical records and patient administration systems (PAS). Questions were developed through a national multi-professional forum and informed by national guidance, health care policy and professional society standards. SAMBA is registered with the Healthcare Quality Improvement Partnership (HQIP <https://www.hqip.org.uk>). The North-West Wales Ethics Committee confirmed that the process for SAMBA described above did not require formal ethical review. Data collection was overseen locally by a named consultant physician.

Given the likely variation in how the presence of ACP may be documented or acknowledged between participating units, ACP was not defined specifically. We asked "Is an advance care plan present?". Although this approach involved a subjective assessment during data collection we felt it provided the most robust method of capturing both written ACPs in physical form and discussions referencing prior wishes contained within the medical notes in the absence of formal documentation. Recording clinicians were asked, in their opinion, if ACP was not in place, would it be appropriate. The presence of ACP was assessed separately from the availability of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) documentation. Follow-up and discharge data were extracted from PAS or clinical records at 7 days.

Statistical analysis

Descriptive statistics were calculated using R studio (Version 1.1.463 – © 2009–2018 RStudio, Inc). 95% confidence intervals were generated for proportions using the HMISC statistical package.

3. Results

Data were collected from 6114 patients. Data regarding the presence of ACP were available from 6072 patients (99.3%), of which, 290 patients had evidence of ACP (4.8%). In patients less than 80 years old the prevalence was 2.9% (95% CI 2.7–3.1) compared with 9.5% (95% CI 9.1–10.0%) in patients aged over 80. In the patients aged over 90

existing ACP between healthcare settings challenging. No uniform approach exists to the documentation and communication of ACP between different healthcare settings and different solutions have emerged in different locations [6]. ACP is associated with increased discussion and documentation of preferences around end-of-life care, increased concordance between documented preferences and care received and reduced stress experienced by bereaved relatives [7-9]. There is some evidence that ACP reduces the need for emergency department visits and inpatient admissions [10–12].

Despite widely held beliefs that ACP is beneficial, uptake is sporadic with considerable variation depending on age, ethnicity, location and disease group [13,14]. There are no national data on the prevalence of ACP but several sources suggest uptake is low, even amongst patients with significant life limiting illness [15-17]. Of particular concern is low rates of ACP amongst frail, older patients, with multiple long-term health conditions but very often with no single over-riding diagnosis [15]. Older people with multi-morbidity and frailty account for a significant proportion of emergency admissions to hospital, yet they are not often considered to be near the end of life by general practitioners, remaining poorly represented in primary care registries of patients approaching the end of life [14]. Identifying those at risk of deterioration facilitates timely discussion and allows practical steps to be taken to ensure care is congruous with individual preferences. In the absence of ACP guidance, hospital admission is the standard pathway of care in response to acute illness. Alternative choices such as prioritising comfort care at home or in a setting other than hospital are extremely difficult to accommodate without a degree of prior planning.

Hospitalisation is an important prognostic sign. Patients admitted to hospital as an emergency represent a high-risk group with a 20% mortality at one year [18]. Mortality increases rapidly with age, such that patients over eighty-five are five times more likely to die in the

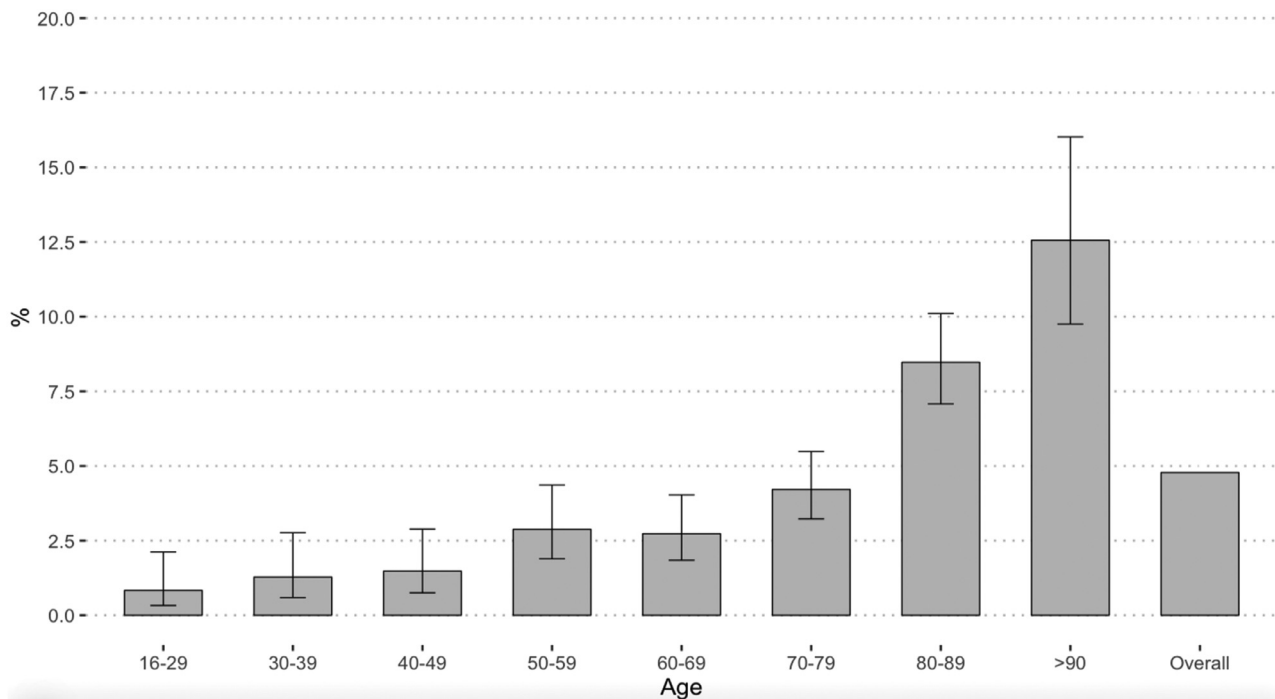


Fig. 1. % of patients with an advance care plan by age.

the prevalence of ACP was 12.6% (95% CI 9.8–16.0). The relationship between age and ACP prevalence is shown in Fig. 1.

Across all age groups, the presence of an ACP was associated with an increased likelihood of the composite outcome of death or continued inpatient status at 7 days. The presence of ACP was more closely associated with this outcome in younger patients. In the patient group below the age of 80 adverse outcomes were reported in 42.5% (95% CI 39.4–45.6) of patients with ACP and 17.5% (95% CI 17.1–17.9%) of patients without ACP. By contrast, in patients above the age of 80, the rate of adverse outcome was similar between the two groups. In patients above the age of 80 with ACP, adverse outcomes were reported in 48.2% (95% CI 45.5–50.8) of cases, compared with 42.0% (95% CI 41.2–42.9) of cases without ACP.

Significant differences were observed in the prevalence of ACP based on location prior to assessment. ACP was more prevalent in patients admitted from institutional care compared with home, 23.3% (95% CI 21.8–24.8%) of patients admitted from institutional care had evidence of ACP compared with 3.5% (95% CI 3.3–3.7) admitted from home.

Where ACP was not available to the direct care team, recording clinicians were asked in their opinion if the presence of ACP would have been appropriate. ACP was felt to be appropriate in 22.3% of cases. The proportion of patients in whom ACP was absent but was felt to be appropriate increased with age. In patients below the age of 80, ACP was deemed to be of potential benefit in 9.4% (95% CI 8.5–10.3) and in the patients above the age of 80, it was felt to be appropriate in 42.2% (95% CI 39.7–44.7) of cases. In patients above the age of 90, without ACP, it was felt appropriate in 60.6% (95% CI 55.6–65.5) of cases.

The relationship between the prevalence of ACP and recent hospital admission was assessed in 1190 patients who had been admitted to hospital in the 30 days prior to assessment. The proportion of patients with ACP increased from 4.2% (95% CI 4.0–4.4) in patients without an earlier admission to 7.1% (95% CI 6.6–7.6) in the recently discharged group. The proportion of patients with ACP increased in the group discharged within the preceding 30 days across all age groups, although the absolute differences were small (Fig. 2).

4. Discussion

Using a national audit of emergency hospital admissions for acutely unwell medical patients within a twenty-four hour period, we provide a snapshot of availability of ACP in UK acute hospitals. Only a small number of patients had evidence of ACP (4.8%). This is similar to previous national surveys which reported 5% of the general population have an ACP or formal living will [22,23]. Demonstrating a similar prevalence of ACP within our cohort is surprising given the high predicted one year mortality associated with emergency medical admission [18]. ACP was rare amongst specific groups at high risk of deterioration such as older patients readmitted within 30 days or living in institutional care. In patients without ACP, reviewing clinicians felt ACP would have been of potential benefit in almost a quarter of cases.

While a significant minority of patients will not want to have ACP discussions many patients think about end of life issues and are willing to discuss their preferences for care [24]. Nevertheless it remains uncommon. In our audit, ACP was not felt to be appropriate in the opinion of the reporting clinician in approximately 40% of patients above the age of 90. This suggests the threshold for initiating ACP is higher than might be expected amongst some clinicians given the predicted mortality following emergency admission in this age group. Several patient, professional and systems factors have been identified as barriers to ACP. ACP conversations are often perceived as difficult and many do not feel adequately educated to undertake them [25]. ACP requires a significant time commitment, often over several visits with a health care professional who knows the patient well, preferably during a period of relative stability [26]. Mounting demands on health care services make this ideal hard to achieve in both primary and secondary care [17,27].

Another difficulty is in identifying when is the 'right time' to initiate a discussion about ACP, particularly when there is no threshold event to prompt this [28]. Hospital admission could be a trigger to offer ACP for a large proportion of patients. Emergency admission to hospital is a poor prognostic sign and frequently signals the transition to end-of-life care regardless of the underlying disease process [18]. If ACP were routinely offered and accepted by patients early in a

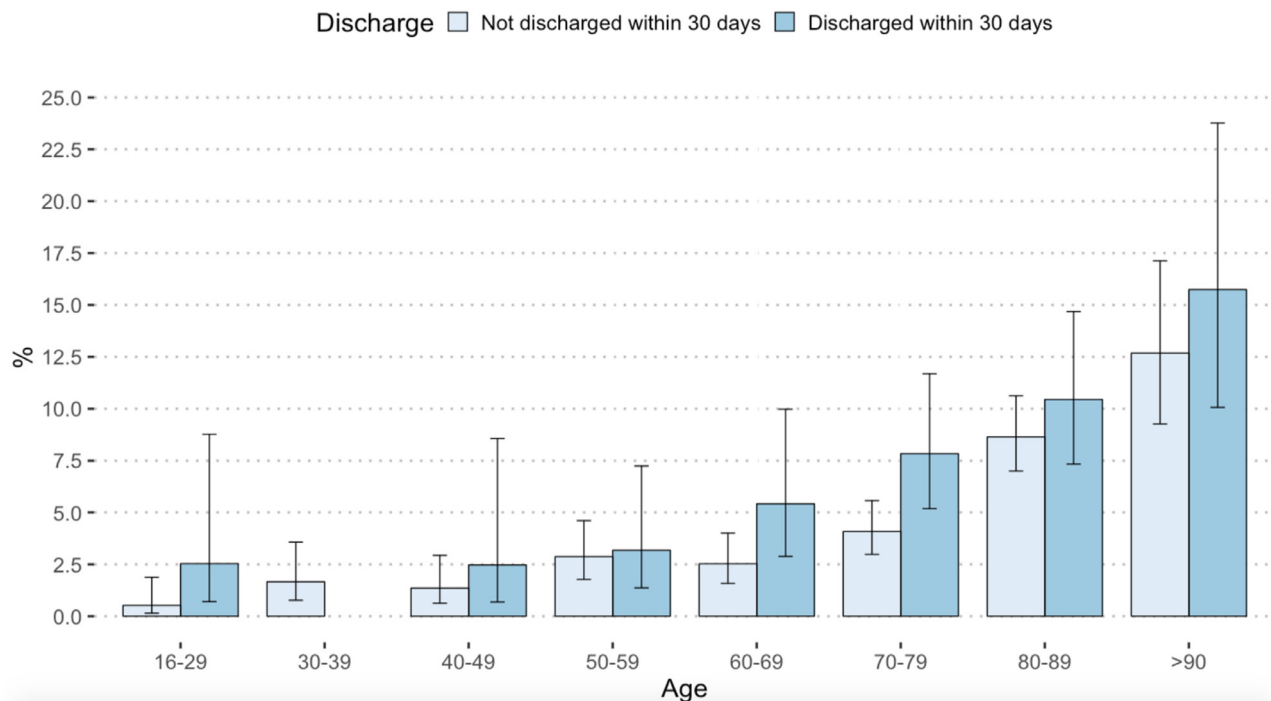


Fig. 2. % of patients with an advanced care plan by age, stratified by admission to hospital within the preceding 30 days.

disease process this would be expected to translate to a much higher prevalence of ACP in this cohort.

The relatively small increment in ACP in patients re-admitted within 30 days suggests it is not undertaken routinely during inpatient care. Whether acute hospital admission provides an acceptable setting for ACP is a matter of debate and individual patients are likely to express differing views [29]. However, systems should be in place to facilitate ACP during admission or in the community soon after discharge. This could include integrating advance care planning into the training of acute physicians, or developing specialist nurses in advance care planning [30]. A recent systematic review has highlighted effective methods for communicating future illness progression and advance care planning with patients [31]. The absence of ACP in the vast majority of re-admitted patients represents a significant missed opportunity to improve care, and highlights a training opportunity for our trainees and nursing colleagues.

Patients with ACP were at greater risk of death or continued inpatient care at 7 days, most likely reflecting differences in the burden of comorbidity between the groups. We were unable to determine location of death from our dataset, therefore ACP may facilitate faster transfer of care to the community but this would not be reflected in our composite outcome measure. When ACP is integrated with palliative care there is a lower adjusted probability of in-hospital deaths [32]. The proportion of patients without ACP within the adverse outcome group increased steadily with age. For patients above the age of 80, death or continued inpatient stay at 7 days was almost equal between those with and without ACP. Predicting the trajectory of decline in frail patients is difficult as many of the cues which prompt ACP discussion in specific disease processes such as cancer are absent. The likelihood of deterioration in this group is often unappreciated and interventions such as offering ACP are overlooked. Strategies to improve access to ACP for these patients should be prioritised.

Whether the low prevalence of ACP observed reflects omission or simply difficulty obtaining the details of prior ACP is impossible to establish. Poor communication during transfer of care between health care settings is a key barrier to effective ACP. Health care professionals are frequently unaware of the existence of ACP and do not

routinely enquire about it [33]. ACP rarely exists in written form, and when it does, it is often inaccurate or lacking pertinent information [17,33,34]. Interventions addressing communication at the interface between primary and secondary care should be a key component of any strategy aimed at enhancing personalised care at the end-of-life. Some initiatives merge nationally recognised documentation about resuscitation with overall goals of care, ensuring that key recommendations for an emergency can be readily identified [35]. This includes, for example when admission to hospital is desired, the ambulance clinicians often need to decide whether to manage a patient at home or whether transport into hospital is required, and there is rarely enough information to guide them [36].

Although this study was a nationally conducted survey which for the first time determined availability of ACP at initial assessment in acute medicine, there are a number of limitations. Firstly, SAMBA is conducted as an audit, not a formal research study [20]. Data collected through audit methods are viewed as applicable only to the settings where data were collected. We have provided confidence intervals where appropriate to facilitate comparisons between groups within the sample rather than to infer generalisability.

Secondly, we did not provide a standardised definition of ACP during the data collection process. To determine the presence or absence of ACP necessitated a subjective assessment during data collection. What form the ACP took and whether sufficient information was present to effectively guide treatment was not assessed. The absence of a standardised definition raises the possibility of variation in the classification of patients at different sites.

Lastly, we did not determine if ACP availability varies at the level of different hospitals, potentially reflecting variation in wider health system approaches. The communication around ACP has been shown to vary in other health systems at institutional level [37]. ACP documentation is a surrogate marker of quality care and not an end in itself. A narrow focus to increase the number of patients with a standardised written ACP document is without gain if the principles of shared decision-making are lost in the process.

The prevalence of ACP amongst patients admitted to UK hospitals with medical emergencies is low even in specific patient groups who are well recognised as being at high risk of death within a year.

Failure to offer and document ACP might represent a missed opportunity to improve and tailor care for patients.

Declaration of Competing Interest

Dr. Fritz is on the executive of the Resuscitation Council (UK), a charity which, among other things, provides guidance on Resuscitation decisions. She also chairs the subcommittee group on ReSPECT, which overlaps with advance care planning. The other authors have nothing to disclose.

Acknowledgments and funding

This project was not directly funded. Professor Lasserson receives salary support from the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) West Midlands and the NIHR Community Healthcare MedTech and In Vitro Diagnostics Co-operative (MIC) at Oxford Health NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NIHR, the NHS or the Department of Health and Social Care.

References

- [1] Statistics, OON, Deaths registered in England and Wales. 2017.
- [2] Marie Curie data briefing: emergency admissions. 2018.
- [3] NICE. Emergency and acute medical care in over 16s: service delivery and organisation. London UK: NG94; 2018.
- [4] Dixon J, King D, Knapp M. Advance care planning in England: is there an association with place of death? Secondary analysis of data from the national survey of bereaved people. *BMJ Support Palliat Care* 2016 p. bmjspcare-2015-000971.
- [5] Rietjens JAC, et al. Definition and recommendations for advance care planning: an international consensus supported by the European association for palliative care. *Lancet Oncol* 2017;18(9):e543–51.
- [6] Capacity, care planning and advance care planning in life limiting illness. a guide for health and social care. N.E.o.L.C. Programme, Editor. London: NHS; 2011.
- [7] Detering, KM, et al., The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. 2010.340: p. c1345.
- [8] Jimenez G, et al. Overview of systematic reviews of advance care planning: summary of evidence and global lessons. *J Pain Sympt Manag* 2018;56(3):436–459.e25.
- [9] Weathers E, et al. Advance care planning: a systematic review of randomised controlled trials conducted with older adults. *Maturitas* 2016;91:101–9.
- [10] Bischoff KE, et al. Advance care planning and the quality of end-of-life care in older adults. *J Am Geriatr Soc* 2013;61(2):209–14.
- [11] Abel, J, et al., The impact of advance care planning of place of death, a hospice retrospective cohort study. 2013.3(2): p. 168–73.
- [12] Engelhardt JB, et al. Effectiveness of care coordination and health counseling in advancing illness. *Am J Manag Care* 2009;15(11):817–25.
- [13] Narang AK, Wright AA, Nicholas LH. Trends in advance care planning in patients with cancer: results from a national longitudinal survey. *JAMA Oncol* 2015;1(5):601–8.
- [14] Thomas K, Corner H, Stobbart-Rowlands M. National primary care audit in end of life care and acp and recommendations for improvement. *BMJ Support Palliat Care* 2012;2(2).
- [15] Sharp T, et al. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *Br J Gen Pract* 2013;63(615):e657–68.
- [16] Butler J, et al. Advance directives among hospitalized patients with heart failure. *JACC: Heart Failure* 2015;3(2):112–21.
- [17] Malyon AC, et al. Discussion and documentation of future care: a before-and-after study examining the impact of an alternative approach to recording treatment decisions on advance care planning in an acute hospital. *BMJ Support Palliat Care* 2017.
- [18] Moore, E, et al., Death within 1 year among emergency medical admissions to Scottish hospitals: incident cohort study. 2018.8(6): p. e021432.
- [19] Subbe CP, et al. A day in the life of the AMU – the society for acute medicine's benchmarking audit 2012 (SAMBA '12). *Acute Med* 2013;12(2):69–73.
- [20] Lasserson DS, et al. Society for acute medicine benchmarking audit. SAMBA 18 report. A national audit of medical care in the UK. *Acute Med* 2019;18(2):76–87.
- [21] Medicine, R.C.o.E.A&E essential facts. 2018.
- [22] ComRes: NCPC dying matters survey /www.comres.co.uk/polls/ncpc-dying-matters-survey 2014.
- [23] De Vleminck A, et al. The prevalence in the general population of advance directives on euthanasia and discussion of end-of-life wishes: a nationwide survey. *BMC Palliat Care* 2015;14:71.
- [24] Simon, J, et al., 'Not yet' and 'just ask': barriers and facilitators to advance care planning—a qualitative descriptive study of the perspectives of seriously ill, older patients and their families. 2015.5(1): p. 54–62.
- [25] Smith AK, et al. Resident approaches to advance care planning on the day of hospital admission. *Arch Intern Med* 2006;166(15):1597–602.
- [26] Zwakman, M, et al., Advance care planning: a systematic review about experiences of patients with a life-threatening or life-limiting illness. 2018.32(8): p. 1305–21.
- [27] Mitchell S, et al. Providing end-of-life care in general practice: findings of a national GP questionnaire survey. *Br J Gen Pract: J R. Coll. Gen. Pract.* 2016;66(650):e647–53.
- [28] Schonfeld TL, et al. Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *Am J Hosp Palliat Care* 2012;29(4):260–7.
- [29] Peck V, et al. Advance care planning after hospital discharge: qualitative analysis of facilitators and barriers from patient interviews. *BMC Palliat Care* 2018;17(1):127.
- [30] Rietze L, Stajduhar K. Registered nurses' involvement in advance care planning: an integrative review. *Int J Palliat Nurs* 2015;21(10):495–503.
- [31] Parry R, Land V, Seymour J. How to communicate with patients about future illness progression and end of life: a systematic review. *BMJ Support Palliat Care* 2014;4(4):331–41.
- [32] Yoo JW, Nakagawa S, Kim S. Integrative palliative care, advance directives, and hospital outcomes of critically ill older adults. *Am J Hosp Palliat Care* 2012;29(8):655–62.
- [33] Heyland DK, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 2013;173(9):778–87.
- [34] Feely MA, et al. Prevalence and contents of advance directives of patients with ESRD receiving dialysis. *Clin J Am Soc Nephrol* 2016;11(12):2204–9.
- [35] Fritz Z, et al. ReSPECT is a personal emergency care plan summary. 2017.357: p. j2213.
- [36] Hoare S, et al. Ambulance staff and end-of-life hospital admissions: a qualitative interview study. *Palliat Med* 2018;32(9):1465–73.
- [37] Heyland DK, et al. Validation of quality indicators for end-of-life communication: results of a multicentre survey. *CMAJ* 2017;189(30):E980–9.