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Amputation and advance care plans: an observational study exploring decision-making and long-term outcomes in a vascular centre

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Abstract

Background: Half of those undergoing major lower limb amputation for peripheral arterial disease die within one year. Advance care planning reduces days in hospital and increases the chance of dying in a preferred place.

Aim: To investigate the prevalence and content of advance care planning for people having a lower limb amputation due to acute or chronic limb threatening ischaemia or diabetes. Secondary aims were to explore its association with mortality, and length of hospital stay.

Design: A retrospective observational cohort study. The intervention was advance care planning.

Setting/participants: Patients admitted to the South West England Major Arterial Centre between 1st January 2019 and 1st January 2021 who received unilateral or bilateral below, above, or through knee amputation due to acute or chronic limb threatening ischaemia or diabetes.

Results: 116 patients. 20.7% (n=24) died within 1 year. 40.5% (n=47) had an advance care planning discussion of which all included cardiopulmonary resuscitation decisions with few exploring other options. Patients more likely to have advance care planning discussions were ≥ 75 years (aOR=5.58, 95%CI 1.56-20.0), female (aOR=3.24, 95%CI 1.21-8.69), and had multimorbidity (Charlson Comorbidity Index ≥ 5 , aOR=2.97, 95%CI 1.11-7.92). Discussions occurred more often in the emergency pathway and were predominantly initiated by physicians. Advance care planning was associated with increased mortality aHR=2.63 (95%CI 1.01, 5.02) and longer hospital stay (aHR=0.52, 95%CI 0.32-0.83).

Conclusions: Despite a high risk of death for all patients in the months following amputation, advance care planning occurred in fewer than half of people and mostly focused on resuscitation.

Introduction

Background/rationale

Limb amputation can be overwhelming for patients, fearing a future of dependency, while still optimistic for an improved quality of life without protracted ischaemic symptoms(1). However, in this period of recovery, few people are offered the space to consider that they may in fact be in the last few months of their life(2). A meta-analysis looking at amputation due to peripheral arterial disease and diabetes found half of patients had died by one year, and almost three quarters by three years(3).

Despite such high mortality associated with amputation from peripheral arterial disease and/or diabetes, a Canadian population-based retrospective cohort study found compared to patients with peripheral arterial disease and/or diabetes only, those who also had an amputation spent more time in hospital in the last few months of life, were less likely to receive palliative care, incurred higher healthcare costs, and were less likely to die at home(4). Since this was a database study, the authors were unable to explore whether any advanced care planning discussions had occurred around participants' surgeries.

Advance care planning can provide patients with the opportunity to align their care with life priorities, personal values and preferences(5). Recognising the importance of this, the guideline body for the Department of Health and Social Care for England (The National Institute of Health and Care Excellence) recommends that advance care planning is offered by services caring for people towards the end of life(6). This may include preferences and appropriateness of treatments including intensive care, renal replacement therapy or ventilation, antibiotics, blood products, and cardiopulmonary resuscitation (CPR) decisions.

Palliative care improves the quality of life of patients facing life-limiting illnesses. The world Health Organisation recommends health systems integrate palliative care services in all levels of care(7). Despite this, a 2014 Veterans Health Administrative dataset study demonstrated that people having a surgical procedure in the last year of their life were less

likely to receive palliative care or hospice services than medical controls(8). A secondary analysis of a randomised control trial studying preoperative communication before major surgery found only 6% of the audio recorded conversations included any statement relating to advance care planning(9). We were unable to find any studies originating from the United Kingdom examining the prevalence of advance care planning discussions in patients undergoing amputation, nor any study that has looked at the whole perioperative period for people having either elective or emergency surgery.

Objectives

Describe the prevalence of advance care planning discussions for patients having an amputation due to acute or chronic limb threatening ischaemia or diabetes. Secondary aims were to: 1) summarise the content of advance care planning discussions; 2) compare the characteristics of the population who do and do not participate in advance care planning prior to amputation 3) assess the association between advance care planning and one-year mortality, and length of stay; 4) assess the effect of the COVID-19 pandemic on advance care planning.

Methods

Study design

We undertook a single centre retrospective cohort study. This study was registered with the North Bristol NHS Trust Quality Assurance and Clinical Audit department (Project ID: QI91739). The study was co-developed with an expert group involved in the care of patients with amputations including vascular surgery, geriatric medicine, and palliative care, and methodologists.

Setting

North Bristol Trust is the Major Arterial Centre for 1.3 million people in South West England. Patients admitted to surrounding hospitals requiring emergency vascular interventions, or

seen in peripheral outpatient clinics, have their surgeries performed by vascular surgeons at North Bristol Trust.

North Bristol Trust has a perioperative medicine service composed of geriatricians. It offers inpatient and outpatient medical support to surgical teams caring for older patients, or those living with frailty. Assessments include medical optimisation and assistance with shared decision making and advance care planning.

Standard practice at North Bristol Trust is to record advance care planning on ReSPECT forms (Recommended Summary Plan for Emergency Care and Treatment). This a standardised tool consisting of a paper pro forma that includes resuscitation status, a person's priorities and which treatment options are appropriate.

Participants

Participants were evaluated against the following inclusion criteria: 1) unilateral or bilateral below, above, or through knee amputation due to acute or chronic limb threatening ischaemia or diabetes; 2) participants are enrolled in Connecting Care - an electronic record system equating to a geographic footprint of Bristol, South Gloucestershire, and North Somerset; 3) surgery undertaken between 1st January 2019 and 1st January 2021 representing 16 months prior to the COVID-19 pandemic, and eight months after the first UK national lockdown 26th March 2020. Patients were excluded if amputation occurred for other reasons e.g. trauma; and alternative amputations e.g. toe, ray, forefoot, or hind-quarter.

Outcomes

Advance care planning was defined as the presence of at least one of: 1) a CPR decision 2) Advance care planning variables as per ReSPECT guidance – Figure 1(10)-(11) 3) Preferred place of death.

Time to death (herein defined as mortality) was the number of days from amputation to death (as assessed on 11th August 2021), patients alive were censored. The time to discharge (herein defined as discharge) was the number of days from amputation to discharge, patients who died in hospital were censored.

Variables

The period of assessment for evidence of advance care planning discussions started with the first interaction with the major arterial centre service. For example, if a patient was admitted as an emergency case but had previously been seen in an outpatient clinic, the starting point would be the first outpatient consultation. Follow-up occurred at 90 days post-amputation and mortality was additionally followed up on the 11th August 2021 for the time-to-event analysis.

Standardised case reporting forms were used to collect: date of birth; sex (male / female); Charlson comorbidity Index (CCI); admission type (elective / emergency) date of death; date of amputation; date of discharge; advance care planning presence and content, desired place of death documented (yes / no), patient capacity (yes / no / not documented), most senior clinician initiating advance care planning (surgeon / physician / general practitioner / other), and in which setting (inpatient – during amputation admission / inpatient – during other vascular admission, inpatient – during unrelated admission / outpatient / community); palliative care referral date; who referred (surgeon / physician / general practitioner / other).

Data Sources

Patients were identified via hospital coding using the following operating procedure codes: amputation of leg above knee (X09.3), amputation of leg through knee (X09.4), amputation of leg below knee (X09.5).

We collected data from three digital care record systems. We were able to view scanned paper notes, copies of ReSPECT forms, outpatient letters, inpatient discharge summaries, and general practice records for comorbidity data and advance care planning documentation.

Statistical methods

We presented the sample descriptively with the categorical variables as percentages and continuous variables as means, medians and interquartile ranges (IQR).

Advance care planning was analysed using a crude and multivariable logistic regression adjusted for: patient age at amputation (under 65, 65 to 74, and ≥ 75 years old); sex; CCI at amputation (mild (CCI 0-2) and moderate (CCI 3-4), severe (CCI ≥ 5)(12)); procedure type (elective, emergency); time (pre-COVID-19, peri-COVID-19). From the analysis we have presented the crude odds ratio (OR) and adjusted OR (aOR) with the associated 95% confidence intervals (95%CI) and p-values.

Mortality and discharge were analysed using a crude and adjusted multivariable Cox proportional hazards regression. The same covariates were included in the Cox model, including advance care planning (yes / no). We have presented the crude hazard ratio (HR) and adjusted HR (aHR) with the associated 95% confidence intervals (95%CI) and p-values. Log-log residual plots were used to assess baseline proportionality. A sensitivity analysis was carried out repeating the mortality analysis with only the emergency cohort of patients. Analyses were carried out using Stata version 16.

Results

Participants

A total of 134 patients were identified through OPCS. Eighteen cases were excluded due to the underlying pathology not being acute or chronic limb threatening ischaemia or diabetes; one case was excluded due to inaccessible notes; one case was excluded as a miscoded hindquarter amputation leading to 116 patients included in the analysis.

Descriptive data

All but two cases had a complete dataset and were included in the analysis as missing but not imputed. The median age of patients at time of amputation was 69 (IQR 61.75 – 74). There were a greater number of men (n=84, 72.4%) and most patients were admitted via an emergency pathway (n=79, 68.1%). Table 1 shows participant characteristics. The one-year mortality rate was 20.7% (n=24). In the time-to-event the median follow up time was 576 days (IQR 391- 748) in the 81 patients alive at the end of the study. More people died in the emergency than elective pathway (Figure 2).

We found that 47 of the 116 cases (40.5%) had some form of advance care planning. In all cases where there was evidence of an advance care planning conversation a CPR decision had been made; 85.1% of these decisions were not to attempt CPR. Advance care planning discussion beyond a CPR decision occurred more frequently in the emergency cohort (Table 2). After CPR decision, the most documented decision focussed on the appropriateness of intensive or high dependency level care (n=19, 16.4%). Capacity was documented in 80.9% (n=38) of the 47 cases where advance care planning was documented.

Physicians completed 78.7% (n=37) of the advance care planning discussions, surgeons 14.9% (n=7), and intensivists 2.1% (n=1). We were unable to determine the speciality completing the advance care planning discussion in two cases. We did not identify any advance care planning discussions having been completed by a general practitioner.

Most advance care planning discussions (59.6%) occurred within the admission of the amputation. Six (12.8%) patients had discussions during a different vascular admission (all were emergency admissions) and 12 (25.5%) were completed on an unrelated admission (all were emergency admissions - 9 medical, 3 surgical). In one case the admission pathway was unclear. Most advance care planning (61.7%, n=29) occurred before the amputation was performed. No patients had an advance care planning discussion in the outpatient setting.

Referral to palliative services within 90 days of amputation occurred in four (3.4%) patients. On average palliative care referrals occurred 18 days before death (range 3 to 42 days). Two referrals were made by a surgeon, one by a physician, and one by an intensivist. Discussions of preferred place of death occurred in all these cases and never occurred without a palliative care referral – although in one case the discussion was had by a surgeon prior to referral.

Statistical Analysis

Main outcome: advance care planning

In the adjusted analysis we found patients that had advance care planning were associated with: being ≥ 75 years old (OR= 5.58 95%CI 1.56-19.96, p=0.008, Table 3), being female (OR=3.24, 95%CI 1.21-6.69, p=0.02), having severe multimorbidity (OR=2.97, 95%CI 1.11-7.92, p=0.03); and during the COVID-19 pandemic (OR=2.85, 95%CI 1.09-7.50, p=0.03). In the crude analysis all findings were consistent with the adjusted analysis, with the exception for patients on the emergency pathway being associated with advance care planning (OR 3.53, 95%CI 1.44-8.68, p=0.006).

Secondary outcomes: Mortality and Length of stay of the index admission

We found an association between mortality with: having advance care planning aHR=2.26 (95%CI 1.01-5.02; p=0.046, Table 4, Figure 3); being female aHR=2.06 (95%CI 1.00-4.24,

p=0.049); and having emergency surgery aHR=2.99 (95%CI 1.01-8.89, p=0.048). There were no differences in findings between those covariates that were associated with mortality in the crude analysis, compared with the adjusted analysis. The sensitivity analysis found an association between advance care planning in the emergency cohort of patients in the crude analysis (HR=2.26, 95%CI 1.08-4.72, Figure 4), but not in the adjusted analysis (aHR=2.03, 95%CI 0.88-4.67).

We also found an association between longer stays in hospital and those that had advance care planning aHR=0.52 (95%CI 0.32-0.83, p=0.007), and faster discharge during the COVID-19 pandemic compared to the pre-pandemic period aHR=1.63 (95%CI 1.05-2.55, p=0.03, Table 5).

Discussion

Key results

Four in ten patients had documented advance care planning. Advance care planning was associated with older people, female, and having severe multimorbidity. It was also associated with higher mortality and longer hospital stay following amputation. The association between advance care planning and mortality is likely to be bidirectional.

Clinicians may be prompted to initiate advance care planning discussions when identifying a patient is at risk of deterioration and death. Additionally, advance care planning may result in life-sustaining treatment being withheld, in line with their expressed wishes, but ultimately resulting in a shorter life.

It may be argued that the higher mortality amongst patients having advance care planning discussion demonstrates appropriate targeting of advance care planning discussions to those most likely to benefit. However, 1 in 4 patients who did not receive advance care planning within 90 days of their amputation died within 2 years. It may therefore be prudent to initiate advance care planning discussions in all patients receiving amputation, even if the outcome of these discussions is that the patient should receive full available treatment.

Our study is consistent with the few North American studies reporting prevalence of advance care planning perioperatively. Two studies evaluating advance care planning prevalence in older adults undergoing high risk surgery found rates of 26% and 33% respectively(13)-(14). One study found a positive correlation between age and advance care planning whilst the other did not.

The rate of do not attempt CPR in this study's cohort was 34.5%. This is higher than has been reported in database studies which have found the prevalence amongst patients undergoing emergency vascular surgery and amputations at 3.3% and 6.8% respectively(15)-(16). This disparity may reflect previous local implementation of the ReSPECT standardised paperwork(17).

Advance care planning occurred more frequently in those with severe multimorbidity, although few patients had mild multimorbidity given the nature of the underlying pathological processes for amputation. A study reviewing advance care planning in acute medical admissions found higher rates of advance care planning in people admitted from care homes and those who had had an admission in the preceding 30 days. It is likely that these patients also had a greater number of comorbidities although the study did not address this specifically(18).

Advance care planning was most frequently completed by physicians. This may reflect differences between physicians' and surgeons' training and subsequent confidence in addressing advance care planning(19)-(20). There remains a paucity of evidence assessing the attitudes of surgeons to advance care planning and no studies found on this topic originating in the UK(21) despite calls for surgeons to take a more active role(22).

Advance care planning was more likely to be performed if the patient was admitted as an emergency than for elective surgery. However, during the adjusted analysis this was not borne out, indicating this was not a factor for advance care planning discussions. Differences may be partly explained by the differences in characteristics between the cohorts, with

elective patients being younger with fewer co-morbidities. Emergency admissions also had a higher rate of mortality and therefore differences observed may reflect appropriate focus of advance care planning discussions(Figure 4). There remains a significant number of patients admitted via the emergency pathway who are dying without advance care planning (Figure 4).

Cases occurring since the COVID-19 pandemic were more likely to have advance care planning documentation. This may be explained by the relative reduction in elective cases during this time but may also be representative of an increased focus on advance care planning since the start of the pandemic(23,24).

Despite high mortality, patients were infrequently referred to palliative care services. Where referrals were made, this was usually in recognition of the person imminently dying. The average duration of palliative care involvement to death was 18 days. A systematic review of 11 996 479 patients across 23 countries found the average duration of palliative care involvement to death to be 18.9 days(25). This is despite maximum benefits of palliative care being realised after at least three to four months(26). A five-year single centre Californian study found only 2.7% (3/111) of patients having an amputation due peripheral arterial disease had been referred to palliative care services prior to amputation and 37.5% (6/16) of those who died within one year received a palliative care consultation(27). The National Confidential Enquiry into Patient Outcome and Death have published a review of the care received by patients who underwent major lower limb amputation due to vascular disease or diabetes. In this they recognise there may be a role for palliative amputation, but often cite palliative management as an alternative to surgery, rather than acknowledging its important role alongside surgical care(28).

Limitations

This was a single site study. Frailty data was not collected. We expect living with frailty to be associated with a higher rate of advance care planning. This is an area that should be

considered for future research. This study did not aim to observe advance care planning in patients with chronic limb threatening ischaemia who reached a shared decision not to undergo amputation. Mortality data was collected from local sources only.

Generalisability

The major arterial centre at North Bristol Trust benefits from a perioperative medicine liaison service of geriatricians. This may result in higher rates of advance care planning being observed here than in other such centres in the UK.

Interpretation

These data suggest a lack of advance care planning amongst a group of patients who are at high risk of dying in the year after surgery. Integrating advance care planning into the preoperative pathway for elective patients undergoing amputation may result in more advance care planning. In addition, most patients admitted via the emergency pathway were already known to the vascular elective service. As such, intervening in the elective pathway would additionally benefit those later admitted as emergency cases.

Future work should also aim to explore the views of patients and clinicians within the pathway to identify the acceptability and optimal timing of advance care planning discussions. It should also aim to improve the quality of advance care planning since in many cases this was limited to CPR decision alone. Additionally, facilitators and barriers to utilisation of palliative care services should be explored.

Declarations

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Conflicts of interest

The Authors declare that there is no conflict of interest

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Research Ethics and Patient Consent

Ethical approval was not required. As this was part of a service evaluation consent was not deemed to be required.

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Tables and Figures

	With ACP documentation (n=47)	Without ACP documentation (n=69)	Total (n=116)
Age mean (median, IQR)	72.0 (71, 66.5-78.5)	64.6 (67, 58-72)	67.6 (69, 61.75 - 74)
Sex ratio (F:M)	21:26	11:58	32:84
Charlson Morbidity Index mean (median, IQR)	6.4 (6, 5-8)	4.6 (5, 3-6)	5.33 (5, 4-7)
Pathway of care %(n)			
Elective pathway	17.0 (8)	42.0 (29)	31.9 (37)
Emergency pathway and previous known to vascular services	57.4 (27)	43.5 (30)	49.1 (57)
Emergency pathway and not previously known to vascular services	25.5 (12)	14.5 (10)	19.0 (22)

Table 1 - Patient demographic data

	Elective (n=37)	Emergency (n=79)	Total (n=116)
Patient variables			
Age mean (median, IQR)	64.8 (67, 60-71)	68.9 (70, 63.5-75)	67.6 (69, 61.75 - 74)
Sex ratio (F:M)	6:31	26:53	32:84
Charlson Morbidity Index mean (median, IQR)	4.9 (5, 4-6)	5.5 (4-7)	5.3 (5, 4-7)
ACP variables addressed % (n)			
CPR	21.6 (8)	49.4 (39)	40.5 (47)
- For CPR	2.7 (1)	7.6 (6)	6.0 (7)
- Nor for CPR	18.9 (7)	41.8 (33)	34.5 (40)
Documentation of capacity	18.9 (7)	39.2 (31)	32.8 (38)
ITU or HDU level care	10.8 (4)	19.0 (15)	16.4 (19)
Ventilation (Invasive or non-invasive)	10.8 (4)	15.2 (12)	13.8 (16)
Renal replacement therapy	8.1 (3)	15.2 (12)	12.9 (15)
Surgical interventions	0 (0)	7.6 (6)	5.2 (6)
Blood products	0 (0)	5.1 (4)	3.4 (4)
IV antibiotics	0 (0)	12.7 (10)	8.6 (10)
Urgent interventions	0 (0)	10.1 (8)	6.9 (8)
Hospital admission	2.7 (1)	10.1 (8)	7.8 (9)
Preferred place of death	0 (0)	5.1 (4)	3.4 (4)

Table 2 - Comparing the patient variables and ACP variables amongst elective and emergency cohort

Table 3 – Association with having ACP with pre-amputation characteristics, presenting the crude odds ratio (OR) and adjusted odds ratio (aOR) with 95% confidence intervals and p-values using a logistic regression.

		Crude OR (95%CI)	p-value	adjusted OR^{&&} (95%CI)	p-value
Age group					
	Under 65	Reference		Reference	
	65 to 74	2.26 (0.89-5.73)	0.09	2.00 (0.67-5.99)	0.22
	75 or older	5.48 (1.86-16.2)	0.002	5.58 (1.56-19.96)	0.008
Sex					
	Male	Reference		Reference	
	Female	4.26 (1.80-10.10)	0.001	3.24 (1.21-8.69)	0.02
Procedure type					
	Elective	Reference		Reference	
	Emergency	3.53 (1.44-8.68)	0.006	2.59 (0.95-7.05)	0.06
Time					
	Pre-Covid	Reference		Reference	
	Since Covid-19	2.29 (1.04-5.03)	0.039	2.85 (1.09-7.50)	0.03
Charlson comorbidity index					
	Mild & Moderate ^{&}	Reference		Reference	
	Severe	3.20 (1.38-7.44)	0.007	2.97 (1.11-7.92)	0.03

[&]Note: Mild and moderate were combined due to few patients categorised as mild

^{&&}Note: Age group, sex, procedure, time and CCI are fitted as adjusted covariates

Table 4 – Association between mortality and pre-amputation characteristics and Advance care planning, presenting the crude hazard ratio (HR) and adjusted hazard ratio (aHR) using a Cox proportional hazards regression

		Crude HR (95%CI)	p-value	adjusted HR (95%CI)	p-value
Age group					
	Under 65	Reference		Reference	
	65 to 74	1.92 (0.80-4.60)	0.14	1.36 (0.55-3.38)	0.51
	75 or older	1.98 (0.75-5.21)	0.17	0.99 (0.35-2.85)	0.99
Sex					
	Male	Reference		Reference	
	Female	2.95 (1.50-5.82)	0.002	2.06 (1.00-4.24)	0.049
Procedure type					
	Elective	Reference		Reference	
	Emergency	4.31 (1.52-12.2)	0.006	2.99 (1.01-8.89)	0.048
Time					
	Pre-Covid	Reference		Reference	
	Since Covid-19	1.22 (0.54-2.75)	0.63	0.84 (0.36-1.97)	0.69

Charlson comorbidity index					
	Mild & Moderate ^{&}	Reference		Reference	
	Severe	1.36 (0.65-2.83)	0.41	0.86 (0.39-1.88)	0.70
Advance Care Planning					
	No	Reference		Reference	
	Yes	3.23 (1.61-6.47)	0.001	2.26 (1.01-5.02)	0.046

[&]Mild and moderate were combined due to few patients categorised as mild

^{&&}Note: Age group, sex, procedure, time and CCI are fitted as adjusted covariates

Table 5 – Association between discharge and pre-amputation characteristics and Advance care planning, presenting the crude hazard ratio (HR) and adjusted hazard ratio (aHR) using a Cox proportional hazards regression

		Crude HR (95%CI)	p-value	adjusted HR (95%CI)	p-value
Age group					
	Under 65	Reference		Reference	
	65 to 74	0.59 (0.38-0.92)	0.019	0.71 (0.45-1.13)	0.15
	75 or older	0.82 (0.49-1.36)	0.44	1.50 (0.83-2.70)	0.18
Sex					
	Male	Reference		Reference	
	Female	0.68 (0.44-1.05)	0.08	0.72 (0.45-1.16)	0.17
Procedure type					
	Elective	Reference		Reference	
	Emergency			0.82 (0.53-1.24)	0.34
Time					
	Pre-Covid	Reference		Reference	
	Since Covid-19	1.17 (0.78-1.75)	0.45	1.63 (1.05-2.55)	0.03
Charlson comorbidity index					
	Mild & Moderate ^{&}	Reference		Reference	
	Severe	0.72 (0.48-1.07)	0.10	0.88 (0.58-1.34)	0.56
Advance Care Planning					
	No	Reference		Reference	
	Yes	0.052 (0.35-0.78)	0.002	0.52 (0.32-0.83)	0.007

[&]Mild and moderate were combined due to few patients categorised as mild

^{&&}Note: Age group, sex, procedure, time and CCI are fitted as adjusted covariates

- Admission to hospital from the community.
- Having intravenous antibiotics for a life-threatening infection.
- Urgent interventions, such as adrenaline for anaphylaxis, seizure control treatment and steroids in Addisonian crisis.
- Receiving organ support, such as renal dialysis or ventilation.
- Having blood products.
- Having an operation.
- Admission to an intensive care unit (ICU) or high-dependency unit (HDU).

Figure 1 - ACP variables as per ReSPECT guidance - developed by the Resuscitation Council UK with the involvement of healthcare professionals and members of the public

Figure 2 - Time to mortality, presenting the Kaplan Meier Plot for all Patients

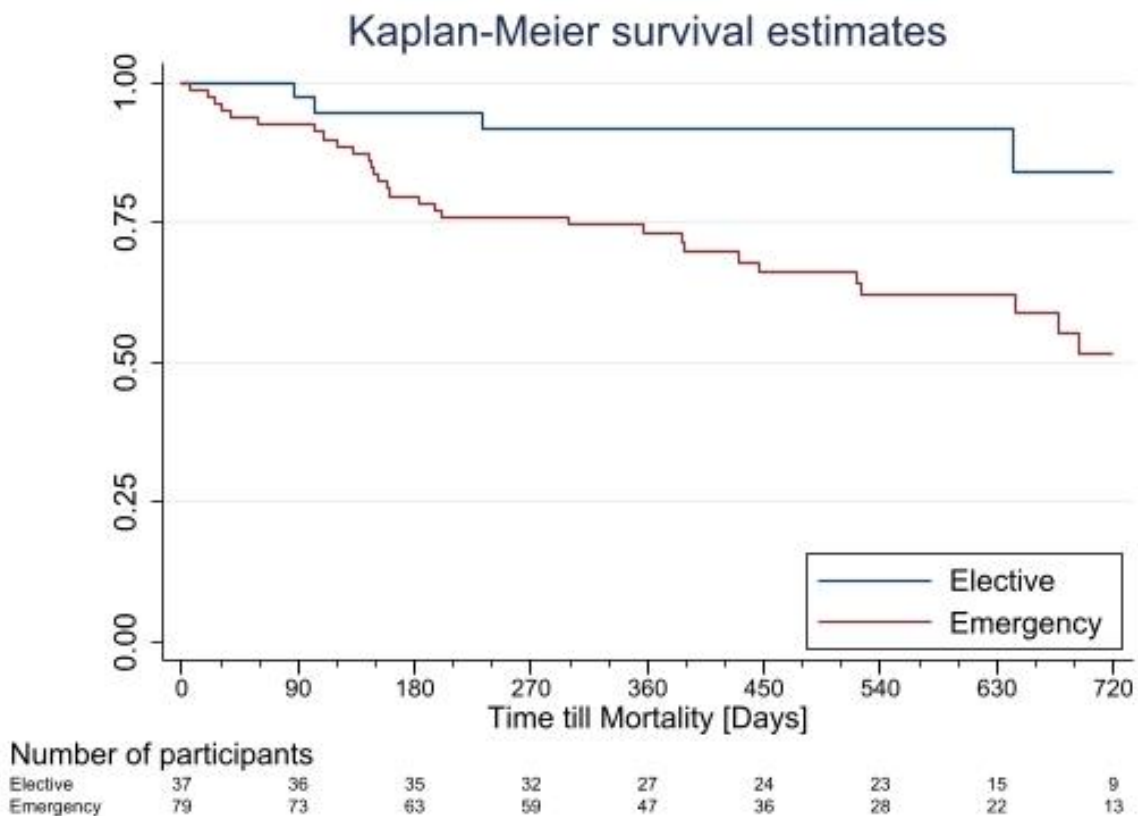


Figure 3 – Time to mortality, presenting the Kaplan Meier Plot for all Patients

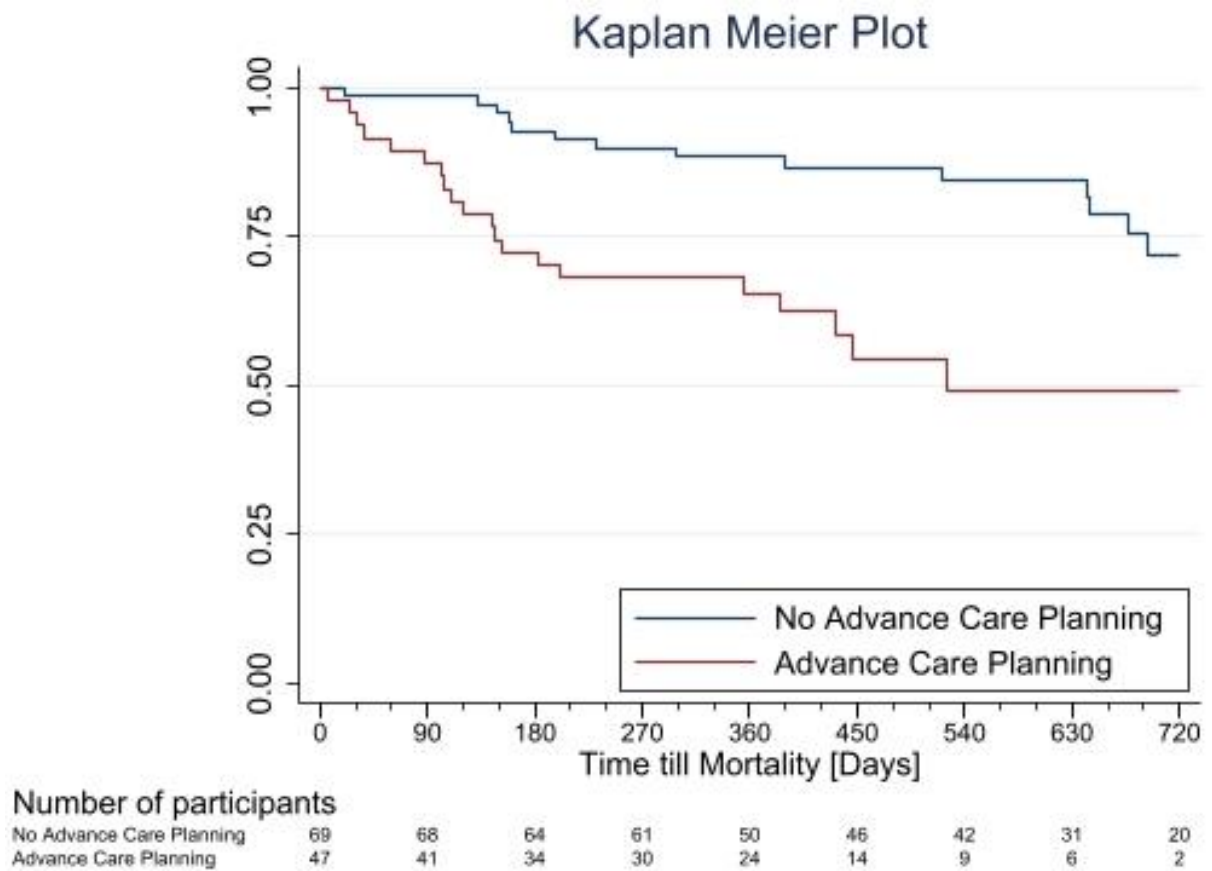
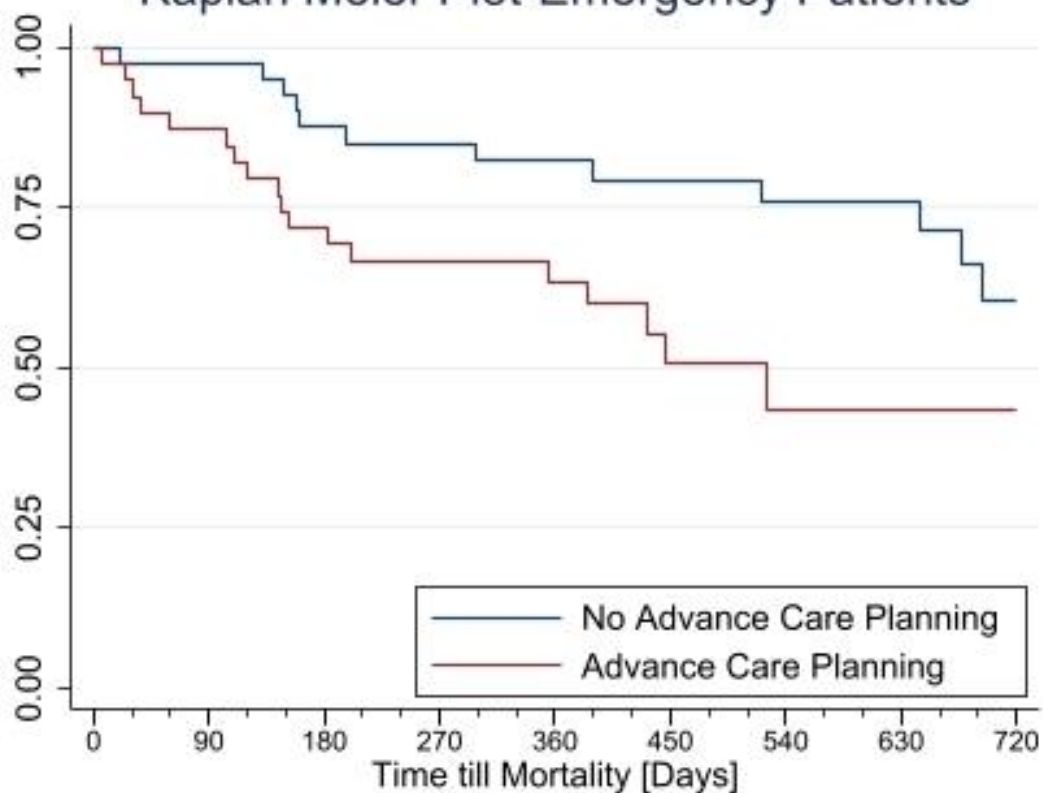


Figure 4 -Kaplan Meier Plot for Emergency Patients only

Kaplan Meier Plot-Emergency Patients



Number of participants

No Advance Care Planning	40	39	35	34	27	25	22	17	11
Advance Care Planning	39	34	28	25	20	11	6	5	2